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OPTIONS IN LONG-TERM CARE

HEARING

BEFORE

THE PEPPER COMMISSION

U.S. BIPARTISAN COMMISSION
ON
COMPREHENSIVE HEALTH CARE

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

WASHINGTON, DC

OCTOBER 5, 1989

PART 8

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OPTIONS IN LONG-TERM CARE

THURSDAY, OCTOBER 5, 1989

The Pepper Commission
U.S. Bipartisan Commission on
Comprehensive Health Care
Washington, DC.

The Commission met, pursuant to notice, at 9:40 a.m., in room G-50 of the Dirksen Senate Office Building, Hon. John D. Rockefeller IV (Chairman of the Commission), presiding.

Present: Senator John D. Rockefeller IV, Senator Dave Durenberger, Representative Bill Gradison, Representative Louis Stokes, Commissioner James Balog, and Commissioner James Davis.

Also Present: Judith Feder, staff director; Edward F. Howard, general counsel; Steven C. Edelstein, Monica McFadden, Robert Friedland, Janis Guerney, Phil Shandler, and Joy Johnson Wilson, professional staff; S. Mitchell Weitzman, staff assistant; and Jackie Shields, intern.

OPENING STATEMENT OF CHAIRMAN JOHN D. ROCKEFELLER IV

Chairman Rockefeller. The second public hearing of the Pepper Commission will come to order please. I might say, at the beginning, that we have a very large number of panels, and that will mean we will have certain constraints, in fact, it already has given us certain restraints.

As you can imagine, we had requests from many organizations and individuals to testify this morning that added up to about 100 witnesses. We would have been here until Thanksgiving Day, so obviously, we had to limit the witnesses who could give oral testimony. If you or your organization is not giving oral testimony this morning, understand, please, that it was because we had to, at some point, break this into five panels.

Could I have silence please in the room? The Pepper Commission has been meeting throughout the summer. We have been listening to experts representing different points of view, questioning, cross-questioning them, and we have done that vigorously.

The Pepper Commission will recommend to the President and to the Congress on both long-term care and the uninsured, and these hearings give us an opportunity to hear formally from the public. We have held field hearings all over the country. We have held town meetings.

The Pepper Commission, if we do our work well, can make an enormous difference in health care in this country.

Today we're going to focus on a problem obviously crying out for a solution—the very real fact that most Americans lack coverage for long-term care. With the help of our distinguished witnesses, the Pepper Commission hopes to take a giant step toward one of our two major goals and that is to recommend a strategy to the President and to the Congress—not just a partial strategy but an entire approach—on how to assure comprehensive, long-term care services to our citizens, when they need them.

Last week we heard eloquent testimony on a different subject, and that was the problems of the uninsured—a vast, incredible, intractable problem that shouldn't exist in our country, but unfortunately does. Over 30 million Americans are uninsured. Another 10 to 20 million Americans are underinsured.

So, we have a large agenda. We know that 9 million Americans, almost half of them under the age of 65, need help with the most basic activities of daily living [ADL].

We know that a need for long-term care poses the risk of financial, as well as emotional, devastation. At the same time, there are no adequate public or private insurance policies available to senior citizens to limit that potential devastation. We know that families provide most long-term care and we know that many families provide it at home. We know that they do it at great cost, emotionally and physically, and that current public policies give no support whatsoever to reinforce these acts of heroism by families going on all over the country.

We also know that the problem is going to grow more serious in the future. We will be listening very carefully to your advice this morning on what direction the Commission should take to address three crucial questions:

One, should we be encouraging people to save money to cover future long-term care costs or devise ways to share the risks through a public or private insurance scheme?

Two, what should the appropriate roles of Government and the private sector be in insuring long-term care?

Three, can we build a long-term care system that delivers long-term care cost effectively? On the Pepper Commission we cannot only deal with the solutions, we are also bound to deal with how to pay for them.

There are those who say that the current controversy over the Medicare Catastrophic Coverage Act makes our long-term care deliberations an empty exercise. Hogwash! It is precisely the opposite. I say, thank God for the Pepper Commission, because I think the Senate is going to repeal Catastrophic Care and I think we, as a Nation, are going to have done something which is damaging in the long term to our seniors. I think it makes the Pepper Commission more important than ever.

We will not, as I said at our last hearing, be intimidated or, for one moment, put off about our responsibilities for long-term care in all of its forms. That may sound naive or it may sound out of touch because I realize it is a very contentious issue, and I realize there are many, including some who will give testimony this morning, who are working very hard to repeal that legislation.

They have a right to their opinions, and I know we'll hear their opinions. As chairman of this Commission and as a Senator from a State that wants leadership and needs responsiveness from Congress on this urgent problem and, frankly, just as a human being, I cannot bear to see these gaps continue. My response is that we simply must forge ahead and mold together a solution for long-term care that has real prospects and that obviously can be enacted.

Until that solution takes effect, millions of Americans of all ages will continue to need long-term care that they cannot get and, as a result, see their life savings evaporate.

We have the chance, I think the obligation, to put catastrophic protection in the larger context of comprehensive coverage and to make solid recommendations that deal with the most catastrophic care problem facing older Americans and their families, as well as millions of younger Americans, and that is the cost of long-term care. I repeat, this is not just a 65-and-older problem. This is a problem that affects millions of Americans, young and old.

Now, I'm going to conclude my remarks by taking off my hat as chairman of the Commission and putting my hat on as a Senator from West Virginia.

Several of my colleagues and I have put together a piece of legislation entitled, the Medicaid Home and Community Care Options Act.

I would like to note with deep gratitude the support and the assistance that I have received from many organizations here and some not here, who have been actively working on this bill which would allow States the option to provide long-term care in the home and in the community.

My bill is one of the incremental steps that I think has to be taken. I still have hopes and I am determined that we will have some success on this during the House-Senate conference. Many of you here have helped on that and I appreciate that.

Now, let's go to our witnesses and welcome all of those Commission members who are here. I would ask if any others have opening remarks.

[The prepared statement of Chairman Rockefeller follows:]

OPENING STATEMENT
by
SENATOR JOHN D. ROCKEFELLER IV, Chairman

at a hearing of the

PEPPER COMMISSION
(U.S. Bipartisan Commission on Comprehensive Health Care)

Thursday, October 5, 1989
Washington, DC

Today's hearing takes our commission one giant step closer to one of our two major goals: recommendations to the Congress on how to assure comprehensive long-term care services to Americans of all ages.

Last week, we heard eloquent testimony, both from families with long-term care problems, and from outstanding experts in the field, that brought home to us the nature and the depth of the long-term care problems facing scores of millions of Americans. Today we ask many of those most closely concerned about a national long-term care policy for their ideas on how to deal with this massive problem.

We know that nine million Americans -- almost half of them _under_ age 65 -- need help with the most basic activities of daily living. We know that long-term care poses the risk of financial, as well as emotional, devastation, but that there is no adequate public or private insurance to limit that potential devastation. We know that families provide most long-term care, and provide it at home, but our public policies do little to support or reinforce that heroic effort. And we know that the problem is going to grow more serious in the future.

We will be listening carefully for your advice today on what direction the commission should take to address these questions.

-- Should we be encouraging people to save money to cover future long-term care costs, or devising ways to share the risk through a public or private insurance scheme?
-- What should the appropriate roles of government and the private sector in insuring long-term care?
-- Can we build a long-term care system that delivers care cost-effectively?

There are those who say that the current controversy over the Medicare Catastrophic Coverage Act makes our long-term care

(Over)

deliberations an empty exercise. My response to them is simply, it need not be so, and we are determined that it not be so. Regardless of the outcome of that fight, Americans of all ages will continue to need care they cannot get, or see their life savings evaporate to pay for costly services, or find their families drained emotionally and physically by trying to care for loved ones at home. Many of you may have watched the poignant reminder of that fact last night on public broadcasting.

We have the chance -- the obligation -- to put catastrophic protection in a larger context of comprehensive reform, and to make solid, bold recommendations that deal with the most catastrophic care problem facing older Americans and their families, as well as millions of others -- the cost of long-term care.

Representative **Gradison**. Mr. Chairman?

Chairman **Rockefeller**. Bill Gradison?

STATEMENT OF REPRESENTATIVE BILL GRADISON

Representative **Gradison**. I can't resist this opportunity after our walk through the fire yesterday. A lot of us got singed, so did a lot of the elderly. Mr. Chairman, there are some good things that can be said, I suppose, about what happened on the floor of the House yesterday. At least they retained the Pepper Commission, and that is something to be grateful for.

It may be a little early to fully interpret the results of what happened yesterday, but I would like to say to the witnesses, and I've looked the testimony over in advance, that it's up to you what you want to tell us, but you're preaching to the choir if you spend most of your time talking about needs. We know about the needs.

I, perhaps, am too close to this, but my view of the problem is raising the money. I find there are some references to that but not a whole lot in the testimony that has been prepared. Put me down as a little negative on the morning after, but I didn't see a whole lot of evidence yesterday that my colleagues in the House are hearing from anybody who wants to spend 10 cents more to help meet the health care needs of anybody but their own families.

I would very much like to be proven wrong on that, believe me. I would certainly encourage witnesses to talk, obviously about whatever you want to, but if you could shed some light on why you think there is any chance in the world of coming up with $50 billion or whatever it would take to deal comprehensively with this long-term plan, I hope you'll tell us about it because it would improve my disposition this morning and probably help us find a solution or move us along toward a solution to these problems.

Thank you, Mr. Chairman.

Chairman **Rockefeller**. Thank you, Bill. Any other comments? Dave, no? Jack, no? OK.

[The prepared statement of Representative Waxman follows:]

ONE HUNDRED FIRST CONGRESS

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WASHINGTON, DC 20515
PHONE (202) 225-4952

OPENING REMARKS
CONGRESSMAN HENRY A. WAXMAN
CHAIRMAN
SUBCOMMITEE ON HEALTH AND THE ENVIRONMENT
OCTOBER 5, 1989

The fears and insecurities of old age and disability are more devastating today than ever before. Aging men and women are desperately worried about where they will spend their last days, how they will get around, and how to cope with the simple tasks of daily living if chronic illness strikes. Families of mentally retarded and physically disabled people and of technology-dependent children are desperately worried about their ability to provide care now and their ability to provide protection once they are gone.

The elderly and families of the disabled are also desperately worried about the heavy burden they may place on their children and even their grandchildren. They know that the emotional and financial drain from a stroke or M.S. or Alzheimer's disease can hit any family and wipe out a lifetime of savings. The annual price tag of $25,000 for services for an elderly person confined to a nursing home or $100,000 for home care for a technology-dependent child is a financial burden that few can shoulder alone.

And today, neither private health insurance nor Medicare offers much help. The frail elderly and the disabled are left with but two choices: they can fend for themselves, or impoverish themselves to get assistance from Medicaid. And that's just not right.

We must develop a Federal approach to long-term care that will assure equal access to both institutional and home and community-based services. Such an approach need not provide for total long-term care coverage. Nor can it depend upon a complete private sector "fix".

The solution, I believe, lies somewhere in between: We need a program with uniform eligibility, benefit, and quality standards which requires significant financial contributions -- throughout a long-term care "catastrophe" -- from those who are better off. For these individuals, private resources such as insurance policies, savings accounts, and pension plans can help foot the bill. But for those who lack the means to pay, a Federal long-term care program must also provide comprehensive financial protections. Such protections include "buy-in" requirements similiar to those now found in the Medicaid program. This is the approach we took in developing the ELDER-CARE program (H.R. 3140), a Medicare long-term care package for older Americans. A similiar proposal might also be constructed for the non-elderly disabled.

But specific solutions aside, we must recognize that it is time to come to grips with this crisis that threatens so many Americans and their families. It is time to face the facts and bring real protection against the financial burdens that long-term care places on so many of our people. Americans want, need, and are willing to pay for long-term care reform. The elderly, the disabled, and their families cannot and should not wait any longer.

Long-term care reform won't be easy and it won't be cheap. It will take enormous resources. It will take Federal leadership and grassroots support. And it will take money. There is no magic free solution to the long-term care crisis. But we cannot let the potential price tag paralyze us.

Those who have been involved with the care and well-being of the elderly and the disabled know first-hand the struggles that come with old age and chronic illness and the need for long-term care. They know, too, that the elderly, the disabled, and their families have carried on this struggle for too long. We must move ahead with long-term care reform legislation that will help ease this struggle. And we must move forward now.

Chairman **Rockefeller**. Our first panel consists of Ronald Pollack, the executive director, Families U.S.A.; Richard Gehring, Alzheimers Association; Frank DeGeorge, the Paralyzed Veterans of America; Lou Glasse, president of the Older Women's League. We are delighted that you are with us.

Let me explain, for a minute, that due to logistics, we had to place the witness table fairly far from the dais. We're physically distant but we are all ears, so please proceed. Whoever wants to go first—Ron, why don't you go first?

STATEMENT OF RONALD F. POLLACK, EXECUTIVE DIRECTOR, FAMILIES U.S.A.

Mr. **Pollack**. Thank you, Mr. Chairman. I hear you although I'm not sure I see you. Mr. Chairman, members of the Commission, before starting I just wanted to thank the congressional members who are here for what I think has been a valiant effort, both on the House side and the Senate side, for trying to protect the catastrophic health care benefits.

I know it has been less than a thankless task. I just wanted you to know that you're not totally alone in those efforts, and a good number of us appreciate what you have been trying to do under difficult odds.

I want to thank you for inviting me to testify and for inviting some of the members of the Long-Term Care Campaign——

Chairman **Rockefeller**. Ron, let me just interrupt for a second. There is an interesting little device in front of you. When it turns red, because we have so many panels, in theory and increasingly in practice, you will no longer be talking. So please try to discipline yourself that way.

Mr. **Pollack**. Thank you. Can we start the clock again?

I'd like to thank you for inviting different members of the Long-Term Care Campaign to testify. The Long-Term Care Campaign involves, at this juncture, a little over 130 national organizations that are members of the campaign. The campaign is primarily funded by Families U.S.A. (formerly Villers Advocacy Associates), AARP, and the Alzheimers Association.

The 130 organizations that are involved are working to place long-term care hopefully as a higher priority national agenda item for meaningful action. We are trying to involve grassroots people around the country and we have active grassroots campaigns in over half of the States. The campaign is as broad as the people who are concerned about long-term care. It is not just seniors who are involved. It is disability organizations, women's organizations, labor, health provider organizations, local government associations, veterans organizations—a wide variety of organizations. We appreciate the opportunity to testify today.

In the brief time I have, I'd like to make three points. Point 1: When we look at long-term care, and hopefully when the Commission looks at long-term care, you look at it as a family benefit and as a family need, not just as a senior benefit or a senior need.

There is often a temptation to talk about long-term care as a senior need. I think that does injustice to this particular issue for a couple of reasons. There are substantial numbers of nonseniors who have chronic disabilities, and they are no less deserving of help than the senior population. Just as importantly, a thoughtful long-term care policy and program should do at least as much for the care giver as it does for the care receiver.

I think you know this from your own observations with the various witnesses who have come before you. Remember the Shindley's who were in front of you about 1 week ago, the family from Los Angeles who put their mother into a nursing home, and the tremendous strain it caused on them emotionally and economically. You noticed it from the Cronkite documentary that was aired yesterday, which many of you had seen beforehand, and the difficulties encountered by each of the families who were portrayed in that documentary—experiences that they had taking care of a loved one.

You certainly have heard it from the testimony of caregivers—a disproportionate number of whom are women. I think by looking at long-term care in this broader family context, not just the senior context, it will inevitably have a profound impact on the benefits you determine should be provided and how they will be financed.

Second, in selecting a priority focus for initial building blocks, I don't believe, Congressman Gradison, that you are likely to be able, in this political climate, to come up with a program all at once which would be a $50 billion program. I don't think any of us would be unrealistic enough to expect that. Although it would be good to have a blueprint in terms of where we ultimately want to go, we don't expect Congress to adopt legislation immediately that is going to be that comprehensive.

So, the question is what are the first important and most needed building blocks that should be created that get us substantially along the way? I urge that the first emphasis should be to provide care in the community and care in the home.

I appreciate so much what you said, Mr. Chairman, about the legislation that you have been leading in the Senate. I think it does take us down that road toward providing care in the home and in the community. I hope that Senator Bentsen is cooperative in the conference proceedings so that the House version, which does incorporate most of what you have in your legislation, will be enacted in the reconciliation bill.

I think home and community-based care deserves priority attention for several reasons. It is because current public policy offers incentives for institutionalization and disincentives for staying in the home and in the community. We don't have a meaningful infrastructure right now in the communities to provide home and community-based care.

I believe home and community-based care, as a general rule, is the place where the people most want their care. It's not for everybody, but I think, generally, it is where people want the care the most.

Let me close with a third and final point. I urge that you do not depend on the private sector insurance as the predominant vehicle in order to provide long-term care. We have already received a variety of reports about the limitations of private sector insurance. You have seen it in the Brookings report, Consumer Reports, and the University of North Carolina reports.

I believe that these are not just limitations in the current products. I believe that there are serious, inherent limitations in long-term care insurance that make it unlikely that the private sector can be relied on to solve this problem.

Let me close by saying that Families U.S.A. Foundation has published a book which I hope has been made available to all of you and your staffs. Authored by Robert Ball, it is titled, Because We're All in This Together—The Case for a National Long-Term Care Policy. In chapter 5 of this book, Mr. Ball does something that I have not seen in previous reports. Namely, he doesn't talk about the current limitations of long-term care private insurance, he talks about the inherent limitations in terms of how we can depend on private insurance to solve our problems in the future.

Thank you, Mr. Chairman.

[The prepared statement of Mr. Pollack follows:]

Testimony by

Ronald F. Pollack
Executive Director

Families U.S.A.
(Families United for Senior Action,
formerly Villers Advocacy Associates)

before the

PEPPER COMMISSION
Washington, DC

October 5, 1989

Chairman Rockefeller and Members of the Pepper Commission, I am honored to be able to testify before you today about how our country can begin meeting the long term care needs of the disabled and of their caregivers.

As Commission members know, Families U.S.A., (Families United for Senior Action, formerly Villers Advocacy Associates) joined with the American Association of Retired Persons two and a half years ago to found the Long Term Care Campaign. Approximately 130 national organizations are members of the Campaign, and the Alzheimer's Association has joined Families USA and AARP as a major partner in funding the Campaign's work.

Our initial public opinion research convinced us that long term care is an unmet need for which Americans of all ages strongly feel a government program is the appropriate solution. Since then, from the moment we publicly announced the campaign to this day, the daily mail has brought heart-rending testimonies from the disabled and their caregivers about the difficulties they have getting and providing long term care, and expressions of hope about what our campaign can accomplish. I know that the Commission, too, has heard these same strong feelings of despair, sacrifice and hope.

This Commission now has the opportunity to respond directly to the unmet long term care needs of a broad section of our population. This Commission has the opportunity to provide relief for the first time to the millions of Americans who need or provide long term care, or will be doing so.

The Commission can accomplish this goal with a plan that provides some immediate assistance and that provides for appropriate future federal government action. In other words, the Commission can design a national long term care policy and put the first building blocks in place. This can be achieved even in our current era of budget constraints.

COMMUNITY CARE

The need that we have all heard expressed over and over again, by the disabled and by their caregivers, is the need for greater access to, and affordability of, community care services. The Walter Cronkite documentary aired nationally this week, "Can't Afford to Grow Old," focuses almost exclusively on families who can no longer provide or afford home care and then can only get assistance when a loved one enters a nursing home.

In 31 states there is a social safety net that provides financial assistance with nursing home care to all who cannot afford such care. These states allow elderly and disabled individuals to qualify for Medicaid, if their incomes are less than the cost of nursing home care and if they have only limited assets. In the other 19 states, elderly and disabled individuals with incomes above a set dollar amount are ineligible for Medicaid assistance with nursing home costs, even if their nursing home expenses exceed their incomes.

The Commission can ensure that there is a social safety net for nursing home care in all 50 states by requiring that all states allow the medically needy, those with medical expenses that leave them with little income, to become eligible for Medicaid assistance.

But in most states, there is no social safety net for those who need financial assistance with community care. Furthermore, since there is no stable funding source for community care, in many places there is no community care delivery system, even for those with sufficient private resources to pay for the services themselves.

A community care benefit should be one of the first building blocks of a national long term care policy. First, it provides for services that are in highest priority demand, and encourages the development of a delivery system that can serve those who can pay with private funds as well. Second, it provides for the affordability of services for which financial assistance is not currently available. Lastly, it redresses the institutional bias of current public policy, which makes institutional services more easily available than community care services.

THE LIMITATIONS OF PRIVATE INSURANCE

Other important initial building blocks of a national long term care policy must define the appropriate role for private long term care insurance. Commission recommendations in this regard must aim to provide consumers with policies that will meet their needs. This can be accomplished by requiring that all policies meet certain standards and by providing insurance counseling for consumers.

In order to develop a realistic national long term care policy, the Commission must acknowledge, however, that private insurance can meet only very limited needs. Costly tax breaks are therefore unwarranted.

The inadequacies of private long term care insurance have been documented now through a variety of research. Brookings Institution researchers Alice Rivlin and Joshua Wiener constructed and analyzed a computer simulation model to estimate the future demand for long term care and to measure how much of that demand private insurance might be able to finance. Their results show that, by the year 2020, even under the most optimistic assumptions, private long term care insurance may account for 7-12 percent of total nursing home expenditures, reducing Medicaid nursing home expenditures by 1-5 percent.

Analysis of 77 typical private long term care insurance plans by James Firman, United Seniors Health Cooperative, and William Weissert and Catherine Wilson, University of North Carolina School of Public Health, showed that most long term care policyholders who enter a nursing home will never collect any benefits. The average probability of not collecting benefits from the 77 plans sampled was 61 percent. Likewise, the vast majority of policyholders who need home care would get little or no help from the policies sampled.

The policies studied by Firman et al. had a third major shortcoming -- inadequate inflation protection. For a person buying a $50-per-day plan, two and one-half years of intermediate level nursing home care, 20 years from now, would leave that individual with $80,000 to $130,000 in out-of-pocket costs, depending on whether or nor the coverage included inflation adjustments.

Consumers Reports enumerated, last year, the inadequacies of most policies on the market and refused to pick a "best buy," citing the high costs and/or limited coverage of available policies. In a recent update, the magazine found that many insurers are now marketing policies with fewer restrictions. Still, many of the older, more restrictive policies remain in force; unscrupulous underwriting practices continue; and the policies with fewer restrictions tend to cost more.

It is important for all of us to realize that the shortcomings of current private long term care insurance policies result from the inherent limitations of the private insurance market, and not simply from the inexperience of the insurance companies with long term care situations. The shortcomings of current policies -- their high costs and restrictive benefits -- will continue.

The need for long term care benefits differs from our need for other insurance benefits. Unlike the need for automobile insurance benefits or homeowners insurance benefits, long term care insurance benefits are not likely to be needed in any one year, particularly by younger persons. The need for long term care becomes more and more probable as we grow older, and becomes most likely for those 85 and older. It can also be a very costly need.

Those likely to purchase long term care insurance voluntarily are those who foresee a need in the near future. Such adverse selection, combined with the high cost of the benefits, makes decent long term care insurance policies largely unaffordable. Faced with similar inherent limitations of private acute care health insurance for the elderly, we established Medicare twenty-five years ago.

The inherent limitations of private long term care insurance are described in a new book entitled **Because We're All In This Together**, published by Families USA Foundation and authored by Robert Ball. Bob Ball is known to many of you as an expert on private and social insurance, and as one of the architects of our Social Security system.

As described by Mr. Ball, private insurance is governed by certain ground rules that are necessary because insurers only have access to a limited market. These rules will effectively prevent private insurance from becoming the primary provider of long term care protection for most middle class Americans, let alone for families of more modest means. The three basic rules are:

Rule 1: Insure only manageable risks;
Rule 2: Avoid ambiguous risks; and
Rule 3: Control induced demand.

Rule One leads private insurance companies to protect themselves against adverse selection. This can be done by refusing to insure those with preexisting conditions that might lead to higher than average probabilities of needing long term care, or by selling policies with limited coverage for preexisting conditions. Rule One makes private insurers hesitant to cover home care, since the need for home care and for specific home care services are difficult to define.

Insurance companies want their obligations to be clearly defined. This can only happen if they follow Rule Two and avoid ambiguous risks. With regard to long term care, this can be done by paying only for certain levels of care, such as skilled or intermediate nursing care, or by paying only for care following acute or skilled care, or by paying only for specific home health services.

Rule Three, control induced demand, discourages private insurers from offering decent home care benefits. Since home care is inherently more desirable than institutional care and since the vast majority of those receiving home care receive it from unpaid family caregivers, home care benefits are likely to be very popular. It is very difficult for private insurers to offer a meaningful benefit, but limit availability at the same time. Government programs are successfully using case management to supplement unpaid caregivers, but private insurance must offer the same benefits to all who have paid their premiums and meet the disability criteria.

Private insurance must necessarily limit the population for which it is obligated to provide long term care. Private insurance will always seek to define its risks by seeking out the healthy and avoiding the sick. Private insurance will always limit its obligation by narrowly defining the covered services. We should not continue to hold much hope that private long term care policies will get better. It is unrealistic to assume that, if we wait long enough, we will be able to leave our long term care needs in the hands of the private sector. Only by adopting a social insurance approach to long term care, and spreading the risk across the entire population, can we meet our long term care needs in an affordable manner.

We should begin now to build a national system. We should begin by addressing our greatest unmet need -- community care. At the same time we can ensure that there is equal access nationally to nursing home care through the Medicaid program. Finally, we can ensure that the private long term care insurance policies on the market will provide meaningful benefits, while understanding that good policies will be out of reach financially for most Americans. Families USA would be pleased to work with the Commission to develop these recommendations.

Chairman Rockefeller. Thank you, Ron. Richard Gehring, Alzheimers Association.

STATEMENT OF RICHARD GEHRING, BOARD CHAIRMAN, ALZHEIMERS ASSOCIATION

Mr. Gehring. Thank you, Mr. Chairman, for inviting me to testify. In your opening remarks, you showed a great appreciation for the problem and expressed it more eloquently than I can. For the record, I'd like to add my personal support and that of the association that I represent for the work you are doing.

Like many members of our association, I am a "family member." My wife has suffered from Alzheimers disease for 15 years. The Alzheimers Association is a national voluntary health organization with 200 chapters nationwide, 1,500 family support groups, and over 30,000 volunteers. We are dedicated to finding a cure and easing the burden on the more than 4 million Alzheimers victims as well as their families and loved ones.

As you have heard, the Alzheimers Association, along with the American Association of Retired Persons, and Families U.S.A., is proud to be a leader in the long-term care campaign. As Ron Pollack has told you, long-term care is not just an elderly problem. It is a family problem. This obviously helps broaden the base of support.

Alzheimers disease illustrates this very well. For every Alzheimers patient, and not all of whom are elderly—my wife was diagnosed at age 49—there are at least three other victims affected by the disease. Most often these are the spouse, the children, the grandchildren, and other members of the family. Families are drained of their financial and emotional resources as the patient steadily loses the ability to understand, recognize people, talk, walk, or even take care of basic bodily functions.

Our families struggle to take care of their loved ones at home, as I did with my wife for 9 years until it was impossible to do so any longer. Only then is the decision made to place them in a nursing home. There, the financial burden becomes unbearable for most families.

I spent $36,000 a year for nursing home care for my wife, and have spent over $200,000 cumulatively. How many families can bear that burden? My wife is only 64 years old and likely to continue living for many years.

Our association has adopted a set of legislative principles for solving this family crisis. Mr. Chairman, I would like to submit for the record, the full list of principles.

Chairman Rockefeller. They'll be included.

Mr. Gehring. I'd like to highlight three of these principles. First, long-term care services should be available to all who need them regardless of age or income. Second, services should be comprehensive, including home care, respite care, day care, as well as nursing home care.

Third, a long-term care program should be built on broad-based social insurance principles where everyone pays and every American who needs the services has access to them. This is an area where we believe private insurance cannot do the job. The association looks to this Commission to take a leadership role in guiding Congress to a comprehensive long-term care solution and to persist until this problem is solved.

We realize that it is going to take time and we really feel gratified that this distinguished Commission is addressing it. Mr. Chairman, we're grateful to you and to other members of this Commission for your legislation to expand home and community-based services for Alzheimers patients, the community care options bill under the Medicaid Program.

We fully support this legislation and hope it will be enacted into law this year. For Alzheimer and dementia patients, one of the most important issues is the eligibility criteria used. Mr. Chairman, I would like to submit for the record, a recommendation on eligibility language.

Chairman ROCKEFELLER. It'll be included.

Mr. GEHRING. The eligibility language in Mr. Waxman's Long-Term Care Assistance Act, Senator Kennedy's Life Care Insurance Plan, and your community care options bill, are all models for you to consider in your deliberations.

We have found that poll after poll shows that overwhelmingly Americans are willing to pay for long-term care protection. They appreciate the risk. They understand it. Americans must feel, however, that the burden of paying for long-term care is spread broadly and fairly so that no one group is saddled with the cost. This is how Congress designed Social Security and Medicare and explains why these programs are among the most popular Federal programs on the books.

If you stick with these principles for long-term care, you can develop a solution that will meet the needs and have the support of the majority of American families and be soundly financed.

Thank you, Mr. Chairman and members of the Commission for your attention.

[The prepared statement of Mr. Gehring and information referred to follow:]

ALZHEIMER'S
ASSOCIATION
Someone to Stand By You.

STATEMENT OF THE

ALZHEIMER'S ASSOCIATION

before the

PEPPER COMMISSION
(U.S. Bipartisan Commission on Comprehensive Health Care)

on

SOLUTIONS TO LONG TERM CARE FINANCING PROBLEMS

presented by:

Richard Gehring

Chairman, Alzheimer's Association National Board of Directors

October 5, 1989

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOC. INC.
70 E. Lake Street, Suite 600 • Chicago, Illinois 60601 • Phone: (312) 853-3060

Thank you, Mr. Chairman, for inviting me to testify today. My name is Richard Gehring and I am Chairman of the National Board of Directors for the Alzheimer's Association. Like many members of our Association, I am a family member; my wife suffers from Alzheimer's Disease.

By way of background, the Alzheimer's Association is a national voluntary health organization comprised of family members, caregivers, scientists, health professionals and concerned citizens. Working through 200 chapters, 1,500 family support groups, and 30,000 volunteers, our Association is committed to finding a cure for this dread disease. At the same time, we are dedicated to easing the burden on the more than 4 million victims, their families and loved ones by supporting the development of better services and proper financing for long term care.

I am here representing not only Alzheimer families and patients. The Alzheimer's Association, along with AARP and Families USA, is a leader in the Long Term Care Campaign, a consortium of more than 130 national organizations seeking a comprehensive solution to long term care financing. You will be interested to know that the organizations in the campaign are from all sectors of our society -- women, the aging, minorities, labor, the physically and mentally disabled, business -- and include in their membership upwards of 60 million Americans.

Long Term Care is a Family Problem

This Commission has gathered extensive testimony in hearings across the country about the need for long term care services, so there is no need for me to go into that today. I do want to reiterate one important point, however, that often gets lost in discussing this issue. Long term care is not merely an elderly problem, as some would describe it. It is a family problem.

Alzheimer's Disease illustrates this best. For every Alzheimer patient -- not all of whom are elderly -- there are at least three victims affected by the disease. Most often these are the spouse, the children and grandchildren and other family members. Families are drained of their financial and emotional resources as the patient steadily loses the ability to understand, recognize people, talk, walk and take care of basic bodily functions. Our families struggle to take care of their loved ones at home, as I did with my beloved wife, until it is humanly impossible to do so any longer. Only then is the decision made to place them in a nursing home, where the financial burden becomes unbearable and the emotional stress continues.

Comprehensive Solution Needed

Our Association has adopted a set of legislative principles for solving this family crisis. These principles closely mirror the principles adopted by the Long Term Care Campaign. With your permission, Mr. Chairman, I would like to submit for the record the full list of principles.

I won't recite all of the principles here. But, several are especially important in light of your deliberations.

First, long term care services should be available to all who need them, regardless of age or income. Means-tested programs, no matter how well designed will always leave too many hard-working Americans without necessary protection.

Second, services should be comprehensive. Most Alzheimer patients are cared for at home and in the community. But, 63 percent of current nursing home residents -- or 940,000 persons in 1985 -- suffer from Alzheimer's or related dementias. Thus, families need the full range of home, community and facility-based services.

Third, a long term care program should be built upon social insurance principles, where everyone pays and every American who needs services has access to them. Private insurance cannot do the job. Policies are too expensive and too limited for most American families.

Building Blocks Toward a Comprehensive Solution

We recognize that with current budget constraints it will be difficult to solve the long term care problem all at once. I find it ironic, however, that Congress can find the billions of dollars to solve the savings and loan crisis, but that health and long term care is considered by some members of Congress to be "too expensive."

Some have suggested that a long term care solution begin with home care; others suggest nursing home care as the first step. Whatever steps are taken, and we hope they are bold, they should be in the direction of a comprehensive social insurance program.

I should mention, Mr. Chairman, that we are grateful to you and other members of this Commission, including Senators Pryor and Heinz and Congressman Waxman, for your legislation to expand home and community based services for Alzheimer patients and the frail elderly under the Medicaid program. We fully support this legislation and hope it is included in the final reconciliation bill. But, no matter how much this legislation is needed, we do not view it as a step toward a comprehensive solution.

Issues of Special Concern to Alzheimer Patients and Families

There are several issues in designing a long term care program that are unique to Alzheimer and dementia patients. The most important is the eligibility criteria used in the program. Traditionally, the simple measure of "activities of daily living" -- or ADL's -- has been used. Unfortunately, this would leave out many Alzheimer patients even though they are in desperate need of help.

ADL's measure functional abilities. Many Alzheimer patients, especially in the early stages of the disease, can demonstrate adequate functional abilities, such as eating, dressing, toileting and the like -- but, only if reminded, guided or supervised. In addition, some Alzheimer patients exhibit problem behaviors that also necessitate supervision. Therefore, to ensure Alzheimer patients qualify for long term care services, the eligibility standards must include the need for supervision or the need for verbal reminding or physical cuing.

Mr. Chairman, I would like to submit for the record a memo on eligibility which gives more detail on the points I have just raised. Also, I would draw your attention to several recent long term care bills, which include eligibility criteria that are especially sensitive to Alzheimer patients. The eligibility language in Mr. Waxman's "Long Term Care Assistance Act of 1989" (H.R. 3140) and Senator Kennedy's "Life Care Insurance Plan" are closest to the mark and with minor changes are models for you to consider.

Americans are Willing To Pay

The key question facing this commission is the willingness of Americans to pay for a long term care program. Some would interpret the response to the Catastrophic legislation as an unwillingness to pay. But, the Catastrophic legislation did almost nothing on long term care and for that reason we believe it is not an accurate test of the public's willingness to pay. Americans understand that long term care needs could strike their family. In poll after poll and by overwhelming margins Americans say they would be willing to pay for long term care protection.

Americans must feel, however, that the burden of paying for long term care is spread fairly, so that no one group is saddled with the cost. This is how we designed Social Security and Medicare and it explains why these programs are the most popular federal programs on the books. If we stick with these principles with long term care, we can develop a solution that will meet the needs and have the support of the majority of American families.

Thank you Mr. Chairman and members of the Commission for your attention. I would be happy to answer any questions.

ALZHEIMER'S ASSOCIATION LONG TERM CARE PRINCIPLES FOR FEDERAL LEGISLATION

The Alzheimer's Association, representing over 4 million people with Alzheimer's Disease and related disorders and their families and caregivers, is particularly sensitive to the unmet need for home, community-based and facility-based long term care and services. Long term care affects all age groups and services should be provided to, and paid for, by all Americans. The Association believes there is immediate need for a federal, universal and comprehensive long term care social insurance program that is "dementia friendly." The Association supports the following principles for long term care reform:

BENEFITS/ELIGIBILITY

1. Eligibility for long term care services in all settings should be extended to all individuals who need them, regardless of age, income, martial status or informal social supports.
2. Eligibility should go beyond traditional measures of disability to include functional, cognitive or behavioral limitations, including the need for supervision because of risk to safety or health or the need for verbal reminding or physical cuing. Eligibility determination should be flexible enough to reflect individual situations.
3. Both public and private long term care insurance programs must cover care provided to Alzheimer's Disease and related disorders patients.
4. Benefits should provide needed services at all levels of care, ranging from a comprehensive system of home and community-based services to facility based services. Services should be provided in such a way as to maintain and enhance personal independence in the community and in the setting preferred by the beneficiary and family.
5. The long term care benefit package should allow maximum flexibility in meeting individual client needs. Direct and indirect services and supplies including items needed to maintain patients at home such as consumable care supplies, should be covered benefits.
6. The program should consider the needs of both beneficiaries and caregivers as appropriate recipients of services. Patient socialization, caregiver respite and other support services should be covered in all settings.
7. Facility based care should be covered in its entirety, regardless of the length of stay.
8. The program should assist families and other informal caregivers. Families should be a primary part of care coordination and beneficiary and family care preferences must be considered in planning and coordinating care. Care coordination should also support, rather than supplant, client and family decision making. There should be no disincentives to family participation; nor should providing informal care be a prerequisite for formal care.

9. Adequate education and training for long term care providers is an essential component of care; provider training must incorporate instruction specific to the care needs of dementia patients. The long term care program should also offer education and training for informal caregivers.

10. The program should ensure high quality care. In order to help ensure quality and access, programs should be monitored, and providers should be carefully screened, well trained and adequately supported and compensated. Efforts to enhance meaningful quality assurance should take special account of the situations faced by patients with Alzheimer's disease or a related disorder.

11. The program should ensure access to services for all. No patient or family should be denied access to information or services because they refuse to relinquish control of care planning to an agency, professional or team.

12. Research should be conducted on more accurate measures of disability and on the adequacy of services to meet patient and family long term care needs.

13. Special provisions should be made to assure that those who lose cognitive function maintain rights to make appropriate care and treatment decisions to the extent of their ability and that their legally designated agents maintain rights to make decisions for them to the extent necessary due to their cognitive impairments.

FINANCING

14. The long term care program should be based on traditional social insurance principles and spread the financial risk as broadly as possible. Its structure should not require the impoverishment of individuals or families.

15. Basic long term care coverage should be made available to all eligible individuals. The program should provide benefits to members of all generations and these costs should be shared equitably across generations. Private insurance may offer supplemental coverage, and standards should be set to protect consumers.

16. Means-tested programs such as Medicaid should not serve as the basis of the federal long term care program; coverage and financing should be uniform throughout the nation and should not stigmatize those in need.

17. The new public program should be supported through sources of financing that are as progressive as possible.

18. Protection from out-of-pocket costs for low and moderate income persons should be provided.

19. Cost containment should be built into the program. The public costs of the program should be minimized while meeting consumer's needs.

ELIGIBILITY FOR LONG TERM CARE: KEY ISSUES FOR ALZHEIMER'S AND RELATED DISORDERS

Many Members of Congress, their staff and the Administration are becoming sensitive to the problems that traditional eligibility criteria create for Alzheimer's Disease and related disorders patients but haven't developed solutions. The major long term care bills introduced in the U.S. Congress in 1988 attempted to cover the cognitively impaired which include Alzheimer's and other dementia patients, stroke patients and others, but did so inadequately.

This memo reviews the problems with traditional criteria and discusses the elements needed to ensure access for dementia patients.

Key elements for eligibility. The following criteria should all be included in legislation (and not left to regulations) to ensure access to services for Alzheimer's and related disorders patients:

- Functional Disability (revised ADL's, + maybe IADL's)
- Cognitive Impairment
- Need for Supervision
- Inappropriate, Problem or Difficult Behaviors

Service needs for dementia patients are complex. No one or two criteria are adequate for separating those who really need service from those who may not. Eligibility criteria must recognize the complexity of dementia and allow flexibility and judgment in assessing the needs of patients.

Traditional ADL's are inadequate. ADL's (Activities of Daily Living) fail to detect disability among dementia patients because they focus purely on physical disabilities. Many with dementia have the skill or physical ability to perform but cannot remember how or when to do so. ADL's should be redefined to include the need for supervision including breaking the task into manageable steps, verbal reminding and physical cueing and other assistance needed to see tasks are initiated, continued and completed appropriately.

Cognitive impairment. Impaired cognition can arise from several types of brain dysfunction or damage and includes a variety of serious problems with thinking, memory, learning, orientation, and perception.

Need for supervision. In addition to the redefined ADL's eligibility criteria should include "need for supervision." Some cognitively impaired patients have no dysfunction with ADL's or only one ADL disability and yet have such poor memory, judgment and thought processes that they cannot be left unsupervised without creating safety or health risks for themselves or others. Dementia patients soon lose awareness of self-care and safety needs.

Problem behaviors. Dementia patients often exhibit behaviors that are dangerous to the safety or health of themselves or others, or are difficult to manage. These problem behaviors lead to the need for supervision and service needs. For example, an informal caregiver is kept awake all night and is unable to pursue gainful employment or to function adequately as a caregiver. The confused, disoriented patient may also wander, get lost, become very agitated or forget to eat.

Alzheimer's Association 70 East Lake Street, Chicago, IL 60601

Chairman ROCKEFELLER. Thank you very much, Mr. Gehring. Lou Glasse of the Older Women's League.

STATEMENT OF LOU GLASSE, PRESIDENT, OLDER WOMEN'S LEAGUE

Ms. GLASSE. Mr. Chairman Rockefeller and distinguished members of the committee, thank you very much for inviting the Older Women's League [OWL] to participate in this dialog with you today. I want to join with my colleagues to commend you for your leadership in seeking basic protections for older people of this country.

I am especially pleased that Congress retained the spousal impoverishment provision and the Medicaid buy-in when the Catastrophic Care Act was repealed. Furthermore, we hope that the Commission will be able to continue its work.

What the public needs and what the people have been waiting for is long-term care coverage. This long-term care coverage must be a universal, social insurance plan open to persons of all ages and economic status who meet the disability criteria. We believe that the furor will not die down until long-term care coverage becomes part of our Nation's health care system.

The Older Women's League was the organization that first brought spousal impoverishment and continued health insurance coverage for persons widowed, divorced, and retired to the attention of Congress. We believe we did not lead you astray in this, and we believe we will not lead you astray in urging the passage of long-term care insurance.

The Medicare and Medicaid Programs are based on acute medical care models. What people really need is an adequate supply of nonmedical, social, long-term care services such as homemaker, chore, adult day care, et cetera. It would be a mistake to buy into the myth that making these services available will lead to informal caregivers coming out of the woodwork to swap their unpaid labor for paid help.

Paid caregivers will never replace the unpaid family caregiver, despite all this nonsense about America warehousing the aged or the decline of the American family. Taking care of one's own remains a deeply ingrained value of our society. Long-term care services will assist the caregiver, but they will never replace her.

OWL's recommendations for long-term care insurance plan include the following: Caregivers, both paid and unpaid, must be given the training, compensation and assistance necessary to provide quality, cost-efficient care without the caregiver sacrificing her physical and financial future.

Our recently completed and most detailed report to date on the status of paid home health care and nursing home aides, and a summary of the report is provided at the end of our written testimony.

Here, I will simply state that the wages, benefits, and working conditions are so poor for these paid caregivers that the turnover rate for nursing home aides is 70 to 100 percent each year, and for home care aides, the annual turnover rate is 60 percent with 80 to 90 percent leaving within 2 years. Their earnings are between $4 and $4.50 per hour. We pay more to parking lot attendants who watch our cars.

The success of any long-term care plan this Commission recommends will hinge on the quality of care these paid aides are able to provide. The program will be doomed unless the plan establishes reimbursement levels higher than under our current Medicaid Program. OWL recommends that the Commission look into wage pass-through programs being implemented in California, New York, and most recently, Michigan that tie increases in State Medicaid funding directly to increased wages for workers.

As for unpaid informal caregivers, the needs of a family caregiver must not be ignored when a needs assessment is done of an eligible disabled person. For too many years, we have enacted Federal programs with complete disregard of the impact on the family caregiver.

When Medicare's prospective payment system was designed so that the hospital would discharge patients quicker, no concern was shown for the caregiver at home who had to fill in the health service gaps, all in the name of cost saving. We are not suggesting that the Federal Government reimburse women for all their long hours of unpaid caregiving. That would be fair, but we realize that Congress and this administration are not yet ready to pay women equitably for the work that they do.

On the other hand, caregiving is a primary cause of poverty for midlife and older women; 11 percent quit their jobs and 20 percent more reduce work hours to perform caregiving responsibilities. Such persons should not also have to sacrifice health insurance and disability coverage. We recommend a health insurance pool, perhaps in Medicare, that primary caregivers could buy into and that Social Security disability coverage be extended to them.

Further, we recommend modification of the SSI [Supplemental Security Income] Program that penalizes family caregivers by reducing the recipient's benefits. Finally, we recommend that our Social Security system be changed so that America's unpaid caregivers not be allotted a zero in their Social Security benefits record for each year spent out of the work force providing care for children and aged parents.

Either these caregivers should be given Social Security credit for the years of hard work, or at a minimum, those years should not be counted in determining Social Security benefits.

Thank you very much.

[The prepared statement of Ms. Glasse follows:]

OLDER WOMEN'S LEAGUE

NATIONAL OFFICE

STATEMENT OF LOU GLASSE,

PRESIDENT OF THE OLDER WOMEN'S LEAGUE

BEFORE THE PEPPER COMMISSION,

A HEARING ON OPTIONS IN LONG-TERM CARE

OCTOBER 5, 1989

730 Eleventh Street, NW ◆ Suite 300 ◆ Washington, DC 20001 ◆ (202) 783-6686

Chairman Rockefeller, distinguished members of the Commission. Thank you for allowing the Older Women's League (OWL) the opportunity to contribute to the dialogue on how best to provide adequate long term care services to all Americans in need of this care.

As President of the Older Women's League, I have had the opportunity on numerous occasions to testify before Congress on health care issues from spousal impoverishment to adult day care to continued health insurance coverage for persons widowed, divorced, retired, or simply layed off.

OWL was the lead organization that brought continued health insurance coverage and spousal impoverishment to the attention of Congress. I think it is fair to say that we have not led you astray when it comes to knowing what the public needs and where the public sentiment lies.

I am now before you to testify on solutions to the long term care crisis facing this country. I have been advised to talk in terms of cost savings in discussing solutions, and I could do that. Some demonstration projects--San Francisco's On Lok, New York's Nursing Home Without Walls, and South Carolina's Community Long Term Care project to name a few--have shown that providing home health care services decreases the number of persons placed in nursing homes. And certainly there are opportunity costs--increased Medicaid, SSI, and other welfare benefits that caregivers need--associated with the current lack of long term care insurance coverage that would be recouped under a comprehensive plan.

But let's be honest. Any desirable long term care solution is going to cost money. What we must address today and what this Commission must determine is how much is the public willing to pay and for what services.

From the beginning of society as we know it, our long term care system has survived off the backs of our nation's midlife and older women--unpaid and unappreciated.

And this exploitive situation would continue if it weren't becoming logistically impossible because of the number of aged and young living with disabilities and diseases that would have killed them a mere five years ago, because of the increased number of seniors and decreasing number of caregivers, and because women, including midlife and older women have to be out in the workforce now ~~because~~ for economic survival.

In finding solutions, I must caution you to not seek short term cost savings at the expense of providing a long term solution that Americans need and will appreciate.

OWL's recommendations include:

1. Caregivers both paid and unpaid must be given the training, compensation and assistance necessary to provide quality, cost efficient care without the caregiver sacrificing her physical and financial future.

OWL recently completed the most detailed report to date on the status of paid home health care and nursing home aides. A summary of the report is provided at the end of our testimony. Here, I will simply state that the wages, benefits, and working conditions are so bad for these paid caregivers that the turnover rate for nursing aides is 70-100% each year and for home care aides, the rate is 60%, with 80-90% leaving within two years. These caregivers are earning between $4.00 and $4.50 an hour. We pay more to parking lot attendants who watch our cars.

The success of any long term care plan this Commission recommends will hinge on the quality of care these paid aides are able to provide. Your program will be doomed to failure from the beginning unless the plan establishes reimbursement levels higher than under our current Medicaid program. OWL recommends that this Commission look into wage pass through programs being implemented in California, New York, and most recently Michigan that tie increases in Medicaid funding directly to increased wages for workers. Rep. Walgren has a similar idea with his bill, H.R. 1649. However, we need to be careful that methods of accountability are developed for the providers to ensure that the money is going to directly to the workers and not elsewhere.

And, of course, we need to provide these paid caregivers with health insurance benefits, which I'm sure this Commission will address in its report on access to health care.

2. As for unpaid, informal caregivers, the needs of a family caregiver must not be ignored.

We are not suggesting that the federal government reimburse women for all their long hours of unpaid caregiving. That would be fair, but we realize that Congress and this Administration are not yet ready to pay women equitably for the work they do.

On the other hand, caregiving is a primary cause of poverty among older women. Studies indicate that approximately 11 percent of women quit their jobs because of caregiving responsibilities. Another 20 percent reduce their working hours. Such persons should also not have to lose their health insurance and diability coverage.

OWL recommends that health insurance pools be formed that these primary caregivers could buy into and that SSDI coverage be extended to them.

We also recommend that there be enough flexibility, in a care plan for the sick and disabled developed under any new system, to assist the family caregiver also.

For example, if a daughter has been providing full-time, informal care to a severely disabled mother for three years, then a care plan under a new long term care system should determine if the informal caregiver needs training, respite from caregiving, a support group, or perhaps special equipment for lifting, toileting, etc.

If during the development of a care plan, it is determined that a custodial care aide is needed, then there should be a provision to allow a family member who is working outside the home the option of becoming the paid caregiver at the same wage rate as what the unrelated custodial caregiver would have received, particularly in rural areas where paid home care workers are in scarce supply.

Many states currently pay neighbors and family members to provide home care under the 2176 Medicaid Waiver program. This same practice should continue under a long term care program. Chairman Rockefeller, you have included such a provision to pay family members in your bill, S. 785, the Medicaid Home and Community Care Options Act. It makes dollars and cents sense to allow flexibility in the program to determine how best to meet the needs of the disabled and aged.

3. We also highly recommend that our Social Security system be changed so that America's unpaid caregivers, the backbone of our health care system, not be allotted a zero in their Social Security benefits record for each year spent out of the workforce providing care for elders or children.

Either these caregivers should be given Social Security credit for their years of hard work, or at a minimum those years should not be counted in determining Social Security benefits. Under current law, women are penalized for each year spent out of the workforce by having a zero averaged in.

4. Legislation, such as the Family and Medical Leave Act, should be enacted to allow family members a temporary, unpaid leave to arrange adequate care for their children, parents, and yes, spouses.

5. In general, OWL believes that any long term care plan should be a universal, social insurance plan open to everyone of all ages and economic status who meets the coverage criteria.

6. A new Long Term Care Commission, including experts in functional assessment for the physically and cognitively impaired would be responsible for refining coverage criteria, setting reimbursement levels, and assessing the program in annual reports to Congress.

The Commission would be similar to the Prospective Payment Advisory Commission. It would be appointed by Congress to advise the Secretary of Health and Human Services on a number of technical issues.

7. Local care coordination councils would act as gatekeepers and would determine an individual's eligibility for services. Based on a comprehensive needs assessment, this council would then develop individual plans of care. The care coordination councils would be a state government agency or a private nonprofit agency that does not provide long-term care services.

8. The program should include a broad range of community and institutional services. Services including, but not limited to: SNF, ICF, skilled nursing at home, comprehensive needs assessment, care coordination, maintenance OT/PT/ST, medical social services, durable medical equipment, consumable care supplies, hospice, home health aide services, homemaker, adult day care [social and health], respite care [in-home and out-of-home], transportation [medically necessary], habilitation, mental health/psychological counseling, home adjustment equipment, speech pathology, respiratory care, personal care services, home and financial management, guardianship, meals-home delivered, minor home and vehicle modifications, protective services.

9. As for financing the program, beneficiaries would be responsible for specified copayments and deductibles. A one month deductible for both nursing home and home health care would be reasonable. For home care, after the first month, a 20% copayment could be implemented. For nursing home care, there could be a 20% copayment for days 31-100, and a 30% copayment after day 100.

High deductibles and copayments are much more severe on the married beneficiaries because the high out-of-pocket costs leave the surviving spouses impoverished.

10. There should be some protection for lower-income beneficiaries. Persons with family income below 200% of poverty should not pay any cost sharing amounts. There should be no assets test.

11. Other financing could come from: eliminating the cap on wages covered by HI portions of FICA payroll tax (perhaps eliminating the cap on the entire FICA payroll tax), reduce estate and gift tax exemption below its current $600,000 level, create a sin tax on cigarettes and alcohol, since they contribute to poor health, and a small increase in Part B premiums.

This combination of financing methods would spread the costs among all segments of the population. Obviously, it will be up to all us, Members of Congress, the President, and grassroots organizations to make sure that everyone understands the benefits and the financing once a consensus plan develops.

We look forward to continuing to work with you and your staff in the development of your report to Congress and in implementing your recommendations. Thank you.

Here are the Facts

Representative Claude Pepper
"As I continue advocating for comprehensive long term care, I will not let my colleagues ignore the concerns of those whose daily work is caring for the elderly and disabled."

Senator John Heinz
"A key to quality long-term care is trained competent caregivers. Federal reimbursement levels must enable long-term employers to compete for the most experienced and dedicated workers."

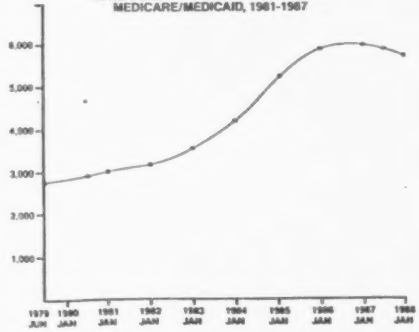
G. Janet Tulloch, Nursing Home Resident and author of "A Home is Not a Home"
"As a nursing home resident, I know that one of the most critical aspects of quality care is having adequate numbers of well-trained nursing aides. Residents who participated in a national study on quality care agreed. Quality care prevails when residents' rights are also employees' rights."

Carolyn Wannish,
Nursing Aide,
Wisconsin, 13 years
"I've been working in nursing homes for over 13 years yet I only make $5.98 per hour; new hires make $4.50! As a full-time employee, I can barely make ends meet. And more and more employers are hiring part-timers so they don't have to pay health insurance."

Nursing Home Aides

- About 1.3 million persons worked as nursing aides in the U.S. in 1986; nearly half worked in nursing homes.
- Nursing aides are virtually all women (90%) and very disproportionately minorities (38% Black and Hispanic).
- Most nursing homes (75%) are for-profit businesses; they employ two-thirds of all full-time equivalent aides working in nursing homes.
- At any given time, nursing homes average the full-time equivalent of 1 registered nurse, 1.5 licensed practical nurses, and 6.5 nursing aides for every 100 beds.
- Nursing aides are responsible for virtually all of the daily personal care of nursing home residents: feeding, bathing, toileting, dressing, moving, etc.
- The average hourly wage for aides in nursing homes is about $4.50. In major metropolitan areas, wages vary from a low of $3.65/hour in Houston to a high of $8.87 in New York City. But many full-time workers and most part-time workers earn less than these averages; thousands work at minimum wage, earning a poverty level wage for themselves and their families.
- According to one national survey, from 1983 to 1988, median hourly wages for uncertified aides in nursing homes increased from $3.35 to $4.32; after adjusting for inflation, the before-tax increase was 2.5%/year.
- Among nursing aides working full-time in major metropolitan areas, most were working in homes that have sick leave, vacations and holidays; about half offered major medical insurance; few had a pension plan. Low-wage workers often cannot afford the premiums and co-payments for employer health plans.
- In many parts of the country, there is a shortage of aides for nursing home work; institutions that hire temporary workers often pay temp agencies double the rates they pay their regular employees.
- Most states do not have specific training requirements and do not certify nursing aides who work in nursing homes.

HOME HEALTH AGENCIES CERTIFIED BY MEDICARE/MEDICAID, 1981-1987



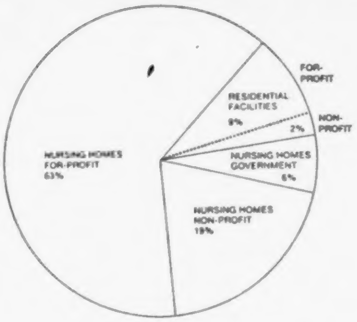
Source: *Health Care Financing Review* 9 (Winter 1987), p. 101

- The Department of Labor projects a need for 425,000 new nursing aides by the year 2000, with nearly all of the vacancies in nursing homes.

Home Health Aides

- At least 300,000 persons work as home health aides in the United States, but little reliable national data about them exists.

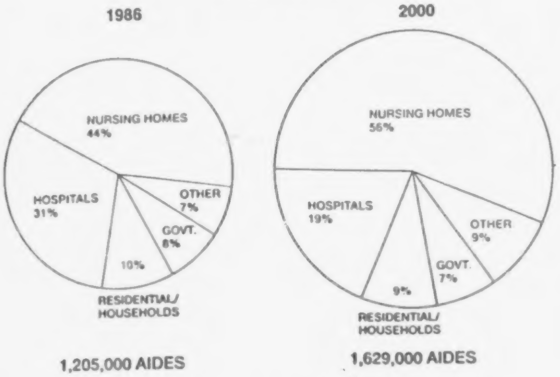
BEDS IN NURSING AND RELATED CARE HOMES



Source: National Center for Health Statistics, Advance Data No. 147

- Like nursing aides, home health aides are nearly all women and are disproportionately Black and Hispanic; most are middle-aged or older.
- The majority of home health aides are single (widowed, divorced or never married) and are the primary economic support for their families.
- Average hourly wages for home health aides are about $4.25, but many work for minimum wage.
- Home health aides earn less than their counterparts in nursing homes, are more likely to work part-time, and are less likely to have any benefits.
- Home health aides are usually not paid for the time required to travel from one patient to another on the same day.
- The majority of home health aides leave their jobs within two years.

NURSING AIDES: OUT OF HOSPITALS, INTO NURSING HOMES



Source: BLS National Industry-Occupational Matrix, 1986-2000, p. 524

Odessa Powell,
Housekeeper, New York City, 11 years (President, Local 389 AFSCME)

"I am proud of my job of caring for the elderly and sick and disabled, but it's hard work and requires a lot of patience and the wages are much too low for the kind of care we're expected to give. If you expect quality care, you must be willing to pay for it."

Elma Holder, Executive Director, National Citizens Coalition for Nursing Home Reform

"The nursing aide is the most valuable yet underrated caregiver in our health care system. NCCNHR urges the public to join us in supporting efforts to improve their training opportunities and increase wages and benefits. They deserve praise and admiration for their work."

Myrtle King, Berkeley, CA
Caregiver Contributor to OWL's *Women Take Care*

"My husband had Alzheimer's Disease. As his condition worsened, I became his mother, nurse, and conservator. He required around the clock care. Outside help would have been a godsend—to have a break from the everyday demands, to be free to breathe fresh air. But there were no caregivers to hire—not even for a day."

Maggie Blanche, AFSCME Retiree Chapter 13, Pennsylvania

"My aunt has to continually get used to new people and that's so hard for her. Especially when you consider that the aides bathe her and take care of her personal needs. Once she gets used to someone, the person leaves and she has to get used to someone else."

Chairman **Rockefeller**. Thank you. Your timing was perfect Lou.

Ms. **Glasse**. Thank you.

Chairman **Rockefeller**. Frank DeGeorge?

STATEMENT OF FRANK R. DeGEORGE, ASSOCIATE LEGISLATIVE DIRECTOR, PARALYZED VETERANS OF AMERICA [PVA]

Mr. **DeGeorge**. Chairman Rockefeller and distinguished members of the Pepper Commission, good morning.

Chairman **Rockefeller**. Frank, can you move the microphone a little bit closer?

Mr. **DeGeorge**. Yes, sir. Thank you. Paralyzed Veterans of America appreciates the opportunity to appear here today, during this extremely important hearing.

We applaud the late Hon. Claude Pepper for his vision in creating the Commission and for your purposeful intent to develop a comprehensive health care program for the Nation's citizens.

Before I go further, I would like to respond to Mr. Gradison's comments earlier about cost and say that Paralyzed Veterans of America supports the statement of Mr. Pollack, as he previously stated, that we are, too, not looking for a full comprehensive program to begin all at once, but in incremented stages and point out that, at the same time, while we're looking at cost, the health care industry at this present time, is already spending like $600 billion a year. So maybe what we need to do is examine what is going on in the health care industry at the present time while looking at a new program.

On behalf of the 14,500 members of Paralyzed Veterans of America, all of whom have incurred catastrophic spinal cord injury or dysfunction resulting in varying degrees of paralysis, I would like to present further our views on the immense need for a completely intergenerational approach concerning access to long-term care.

A spinal cord injury can happen to anyone at any age. However, the initial spinal cord injury usually occurs at the average age of 25 or younger, pointing out that the need for health care is a long-time, life-time need.

I'm going to lay aside part of my testimony and go right to something that Paralyzed Veterans of America is very much in concern with. That is, of course, why, and you might ask, should a veterans service organization come before this Commission, and advocate the creation of a national health care insurance program to include comprehensive long-term care for all Americans?

In the first place, because of restrictions of eligibility and entitlement, not all veterans are eligible for the full range of medical service provided by the Department of Veterans Affairs [DVA]. In 1990, more than one-half of all American men over the age of 65 will be veterans. The demands placed on the VA medical system by the aging World War II and Korean war veteran population during the next two decades will be intense.

Ninety-five percent of all inpatients of the Veterans Administration medical system are either service-connected, disabled veterans, or veterans in the lowest income categories. The vast majority of these veterans in the latter category are the uninsured, the uninsurable, and by the time they reach a VA medical center, are medically indigent.

The DVA cannot provide the necessary long-term care services and an adequate national program is not available to meet their needs. These veterans will merely join the ranks of millions of other Americans who have fallen through the cracks of a disjointed and ill-prepared national care health system.

Second, even at restrained levels of funding, the Veterans Administration medical system is still the Nation's largest health care provider and a major national health care asset. The DVA health care program is also one of the most underestimated and unrecognized health care safety nets in the United States.

PVA is concerned that as the Bipartisan Commission deliberates to make recommendations to provide national programs improving access to health care and long-term care services for all Americans, that you might be overlooking the potential impact such a program might have on VA health care.

Likewise, the reciprocal applies in potentially overlooking the influence the DVA health care programs might have on the new national health care system in the context of the demand for, and the provision of, services.

Mr. Chairman, we need to underscore our concern that the need for long-term care goes far beyond those generations of Americans over the age of 65. Long-term chronic disability is in many ways a young person's lifetime problem, affecting not only the disabled person, but everyone surrounding the individual for a matter of years and decades.

Thank you and I will be glad to answer any questions you may have.

[The prepared statement of Mr. DeGeorge follows:]

PVA
PARALYZED VETERANS
OF AMERICA
Chartered by the Congress
of the United States

STATEMENT

OF

FRANK R. DEGEORGE, ASSOCIATE LEGISLATIVE DIRECTOR

PARALYZED VETERANS OF AMERICA

BEFORE

THE PEPPER COMMISSION

UNITED STATES BIPARTISAN COMMISSION ON

COMPREHENSIVE HEALTH CARE

CONCERNING

LONG-TERM CARE: OPTIONS and FINANCING

OCTOBER 5, 1989

Chairman Rockefeller and distinguished members of "The Pepper Commission," The United States Bipartisan Commission on Comprehensive Health Care, I am Frank R. DeGeorge, Associate Legislative Director of Paralyzed Veterans of America (PVA), a Congressionally chartered veterans' service organization. PVA appreciates the opportunity to appear here today, during this extremely important hearing. We applaud the late Honorable Claude Pepper for his vision in creating the Commission and for your purposeful intent to develop a comprehensive health care program for the Nation's citizens.

801 Eighteenth Street, N.W., Washington, D.C. 20006 (202) USA-1300 Fax: (202) 785-4452

On behalf of the 14,500 members of Paralyzed Veterans of America, all of whom have incurred catastrophic spinal cord injury or dysfunction, resulting in varying degrees of paralysis, I would like to present our views on the immense need for a completely intergenerational approach concerning access to long term care.

Since its founding in 1947, PVA has been in the forefront of the effort to ensure that veterans receive quality medical care and rehabilitation through the provision of specialized assistance for veterans with spinal cord injury (SCI) or dysfunction. In addition, PVA strives to assist all disabled individuals through a broad range of programs designed to provide fuller access to society. Paralyzed Veterans of America is one of the Nation's largest private sources of funding for research in the field of spinal cord injury. We also support an SCI health care professional education foundation; programs providing accessibility through architecture and barrier free design; one of the Nation's largest wheelchair sports program to enhance rehabilitation; and a nationwide service officers corps that provides direct benefit counseling and assistance for our members and all veterans.

Prior to the 1940's, few individuals survived a spinal cord injury. However, with the development of antibiotics during World War II, and subsequent medical advances, the life expectancy of an individual with a spinal cord injury today, is nearly the same as the average life-span for the population at large. With survival and increased longevity has come the need to learn how to cope with the myriad of activities of daily living, improve the quality of life, and find solutions to the many on-going problems, both social and medical, associated with spinal cord injury and dysfunction.

A spinal cord injury, resulting in paralysis, can happen to anyone, at any age. However, statistics have shown that, on the average, the initial spinal cord injury usually occurs at the average age of 25 or younger. At this age, the spinal cord injured individual is faced with a lifetime of living with the full consequences of catastrophic disability. Nationwide, there are approximately 500,000 persons who have incurred either a spinal cord injury or dysfunction, with an incident rate of 9,000 new SCI injuries per year.

The disheartening question a newly injured person must ask is, "what am I going to do for the rest of my life?" The injury is of such an enormous consequence that it will ultimately affect the lifelong welfare of the individual, family members, friends, and, eventually, all of society. The nature of a spinal cord injury and subsequent rehabilitation requires the direct and on-going involvement of others; it simply can't be avoided. It is a road that no one could or should travel alone without the needed support of others, no matter how independent they become. But, quite often, because of social and physical barriers, expense of care, and a lack of adequate support services, many spinal cord injured individuals must face these challenges alone.

After injury, the SCI individual is first confronted with the combined arduous tasks of medical and physical rehabilitation. This process can take months, even years. After deinstitutionalization, many severely disabled individuals face a lifetime need of long term care and custodial service that begin every morning and end every night. These services are most often (but not always) supported by the family members, whether they be the parents, or a spouse, or a child. This is a tremendous undertaking, and when it works, the success can be attributed to traditional family ties and the love of one for another. When it doesn't work, an individual must look at government services, or private services, or insurance programs, all of which are totally inadequate to meet the constant demand for care and the catastrophic lifetime expense of these services.

While there are many varying and dramatic reasons for this situation, the most common is that either the spinal cord injured person and/or the caregiver is overwhelmed by the demanding efforts concerned with the tiring and costly delivery of providing the necessary care each day without relief. Then there is the reality that the caregiver is in frequent need of consideration of his or her health. During their lifetime, almost all of the 37 million disabled Americans and a growing population over the age of 65, and their family caregivers, are or will be faced, at some point in time, with the continuing need of supportive types of long term care.

Such programs offered are respite care, personal care assistance, custodial care, continued medical care, intermittent and/or long term nursing home care, to name a few. The individual on his own cannot afford these personal needs, especially today when nursing home care exceeds $35,000 a year. The cost for only four hours of service by a personal care attendant ranges from $50 to $100 or more, even if quality attendant care services are available in the community. Regardless of income, the cost to sustain this care is astronomical. There are no adequate insurance policies or government programs that can adequately meet these needs.

It is clear that the national budget deficit is a problem that is driving health policy as well as policy in many other major domestic program areas. Funding reductions are usually arbitrary and are made irrespective of the direct and indirect impact on the ultimate beneficiary. Providing health care in the United States needs to be adequately addressed. If it is not, it will continue to result in a disjointed health policy where decisions are influenced by mechanisms that are effective in contributing to cost reduction - short run solutions - rather than longer term strategies for total change and realignment.

Realizing full well the ever-increasing costs associated with nursing care, especially for the chronically ill or long-term disabled, alternatives to institutional care need to be developed. An individual who can no longer obtain family support or afford attendant care services can readily lose whatever independence from this disability they have been able to achieve and be forced into a lifetime of expensive and dehumanizing institutionalization. However, even those who have support from families or friends are threatened by the same consequences.

For this reason, PVA, in addition to calling for an adequate home care program for those disabled individuals in need who have no other resource, strongly supports the implementation of a national respite care program. Respite care can provide short term relief from the responsibilities of caring for a chronically ill or disabled family member, while helping to maintain the family equilibrium to continue that care. Respite care programs serve elderly or impaired individuals who want to remain at home, and care givers who want to care for the relative or spouse at home.

In July, in response to a nationwide survey, PVA received a letter from the mother of a veteran who speaks very clearly and intimately of the day-to-day strain of caring for a loved one with a catastrophic disability. Her son was stricken with multiple sclerosis 19 years ago. She is his only means of direct daily care:

> "I really feel nobody cares about a parent who is taking care of a disabled person - much is said about wives and children, but parents are rarely mentioned. My son's wife divorced him after he got sick. Her mother convinced her that her life would be horrible taking care of a sick man. So he came home to me, and I've been taking care of him for 19 years now. I sleep in a chair, by his bed, and know every time he wakes up. This is day and night duty.
>
> I have never been able to go shopping or to a movie or to lunch, without a great deal of trouble to find a sitter. God, forgive me if I sound like I'm complaining - I'm really just trying to explain how it is. I wouldn't have it any other way. I love him very much and wish I could do more for him."

In another example, the wife of one very disabled quadriplegic man explained that her level of satisfaction varied with her degree of burnout. Two years ago she found herself yelling and screaming daily and subsequently left for a month. The respite was a "godsend," she said - without it they would "probably be divorced" or she would be in a "rubber room." She reported similar symptoms recently and knew she needed another break. Another wife of a quadriplegic described her feelings about her caregiver role: "I hate it. I really don't like it, but I don't have a choice." She mentioned times when she "ranted and raved" about her situation. She wanted to go away for a day or two to "get away from it all," but she could not because of insufficient attendant care and money.

A respite care program will offer health care in the home environment in lieu of an institutional setting. Realizing the ever-increasing cost associated with care provided in a hospital or in a nursing home, respite care can prove to be very cost effective. The cost of providing three hours of care daily by a licensed practitioner in the home is considerably less than the cost of three hours of any service provided by a hospital or nursing home, even if such services were available. We encourage the Commission to make certain that an adequate program of home care services and respite care assistance for disabled Americans of any age are included as an integral part of your National health care proposal.

Why, you might ask, should a veterans' service organization come before this commission and advocate the creation of a national health care insurance program to include comprehensive long term care services for all Americans? Aren't all of our health care needs provided for by the Department of Veterans Affairs? Hasn't a grateful Nation already supported the VA health care system to provide an integrated program of inpatient, outpatient and long term care services for any veteran in need? The answer to these questions and the reason for our presence here today must be given in two parts: first, to explain what the Department of Veterans Affairs can't do; and second, to describe what it can.

In the first place, because of restrictions on eligibility and entitlement, not all veterans are eligible for the full range of medical services provided by the Department of Veterans Affairs. Basic access, apart from veterans with disabilities incurred in services who are placed in the highest eligibility category, are means tested. However, low income veterans who might receive priority for inpatient services, because of ambiguities in the law, might not receive the same priority for outpatient services. Long term care services, including nursing home and home health services, are even more severely rationed.

In 1990 more than one-half of all American men over the age of 65 will be veterans. The demands placed on the VA medical system by the aging World War II and Korean War veteran population during the next two decades will be intense. The Department is already reeling from the impact of soaring medical inflation rates and decremental budgets over the past eight years that have forced the VA medical system to severely ration services and treatment even for veterans who are eligible today - not to mention preparing to care for those who will need services in years to come.

For instance, the last Administration placed a virtual moratorium on the construction of new nursing home beds. During the same period the Office of Management and Budget (OMB) refused to increase funding for home health care, adult day care and respite care programs. OMB considered these long term care initiatives a stimulus for demand and expense, not a potential cost-saving alternative to nursing home care. Also under the instructions of OMB, the Department has been unable even to modify significant numbers of available but underutilized acute care beds for nursing home beds for the same reason.

The purpose behind these restrictions is very clear from an accounting standpoint but totally unrealistic in the end result. The VA medical system does not have to pay for the care of a veteran if the beds and the resources are not available to provide that care. However, veterans denied care in the VA system do not, like the old soldiers in the poem, "just fade away." They have to seek services, particularly in the case of treatment for catastrophic illness and long term care, from other already over-burdened federal, state or private health care programs and providers. What has then become a cost-saving for the Department of Veterans Affairs, has, in reality, become a major cost-shift to other government programs or private sector providers already overwhelmed by the burden of uncompensated care.

Ninety-five percent of all inpatients in the VA medical system are either service-connected disabled veterans or veterans in the lowest income categories. The vast majority of these veterans in the latter category are the uninsured, the uninsurable and, by the time they reach a VA Medical Center, the medically indigent. If the DVA cannot provide the necessary long term care services, and an adequate national program is not available to meet their needs, these veterans will merely join the ranks of millions of other Americans who have fallen through the cracks of a disjointed and ill-prepared national health care system.

Secondly, even at restrained levels of funding, the VA medical system is still the nation's largest health care provider and a major national health care asset. The DVA health care program is also one of the most underestimated and unrecognized health care safety nets in the United States. PVA is concerned that as the Bi-Partisan Commission deliberates to make recommendations to provide national programs improving access to health care and long term care services for all Americans, that you might be overlooking the potential impact such a program might have on VA health care. Likewise, the reciprocal applies in potentially overlooking the influence DVA health care programs might have on the new national health care system in the context of the demand for and the provision of services. Certainly, millions of veterans currently depending upon service in the VA health care system would have access to alternative sources of care under such programs. But others not previously enrolled might be referred to the VA in lieu of other insurance coverage actually creating an increase in demand for the Department.

Contrary to popular opinion, the Department of Veterans Affairs does not stand alone in the national medical scene. VA medical centers are highly interconnected with affiliated medical schools, and public and private medical research institutions. VA's major medical, prosthetic and rehabilitation research programs have provided major advances that have benefited both veteran and non-veteran alike.

Currently, the VA system serves as the nation's single largest health manpower production resource. Nearly one-half of all the health care professionals in the United States have received all or part of their training through the VA system. In its role as a health care safety net, VA medical system provide comprehensive acute care and long term care services for hundreds of thousands of individuals with chronic medical and psychiatric disabilities - a patient load that could not readily be absorbed by any other health care system or entity. The DVA is a major provider of drug and alcohol treatment and currently provides complete care for approximately 10 percent of the nation's AIDS patient census, a figure which is estimated to rise significantly in the near future.

As you know, several states are considering or are already in phases of implementing major new health care insurance programs that would greatly expand access to health care services for large numbers of uninsured or under-insured citizens. Recognizing this fact, PVA is already in the development stage of a major research project and survey designed to track, as an initial example, the implementation of the new "Massachusetts' Health Security Act of 1988". The implications of monitoring this new program at the state level could have major consequences in revealing how the Department of Veterans Affairs can successfully interact from a standpoint of utilization and resources with a new national program. We would be happy to discuss these efforts with the Bi-Partisan Commission.

Mr. Chairman, in conclusion, on behalf of the members of Paralyzed Veterans of American, I would like to express our appreciation for the monumental task before you in drafting a comprehensive health care agenda, to include long term care services, for the Nation. Never has this need been greater as the average American grows older and stays older longer.

At the same time, we need to underscore our concern that the need for long term care goes far beyond those generations of Americans over the age of 65. Long term, chronic disability is in many ways a young person's life-time problem, affecting not only the disabled person but everyone surrounding that individual for a matter of years and decades. We can improve the quality of life and the productivity of life for disabled individuals, but only if we care enough to make certain that those who have no other resource to care can receive the services they need.

Over the past two years, the federal government, at the direction of the Administration and the Congress, has made great strides in recognizing the needs and the values of disabled Americans. The Civil Rights Restoration Act, the Fair Housing Act in the last Congress and the on-going progress in passage of the Americans With Disabilities Act this year, have gone a long way in finally providing the government mechanisms to ensure equal opportunity and access to society for all disabled citizens. The provision of equal access to health care and protection from the catastrophic cost of long term care for all Americans, regardless of age or disability, should be the next mandatory step in this process.

Thank you for the opportunity to present our views here today. I will be happy to answer any questions you might have.

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BIOGRAPHY
OF
FRANK R. DeGeorge

Frank has proudly served Paralyzed Veterans of America, a Congressionally chartered veterans service organization, in many and varied capacities as an elected, appointed and volunteer representative. In 1979, he accepted employment with PVA, and presently, he is serving as an Associate Legislative Director.

Frank was born on December 1, 1936, in Chicago, Illinois. Frank's marriage to the former Patricia J. Izzo is complimented by their three children: Debbie, Julie and Frank, Jr., and three grandchildren.

Frank served in the U.S. Army from 1954 to 1958 and was honorably discharged. Undaunted by an injury in 1963, resulting in spinal cord injury as a C5-6 quadriplegic, Frank became an involved member of PVA. He served as PVA National President from 1972 until 1974; he was responsible for activities and mandates of the organization while seeking the best medical care and benefits for all veterans on behalf of PVA.

Among his many honors, Frank is the proudest of PVA's highest award, which he received in 1977, the "Speedy Award," for his "most significant contribution" to the advancement of disabled people in the field of paraplegia.

801 Eighteenth Street, N.W., Washington, D.C. 20006 (202) USA-1300 Fax: (202) 785-4452

Chairman **Rockefeller**. Frank, thank you very much and thank all of you. We welcome questions now from members of the Commission.

Commissioner **Davis**. Thank you, Mr. Chairman. Our first two speakers emphasized the fact that our private insurance system should not be expected to carry the whole load of long-term insurance coverage. What role and how large a role do you see the private insurance system playing in the financing of long-term care?

Mr. **Pollack**. Well, as I said, my concern is that we should not expect the private sector to be the predominant vehicle by which we are going to provide protection for long-term care. I don't presume it's going to be all or nothing, all private sector or all public sector. There is going to have to be some kind of a mix.

My caution, however, is in assuming that the private sector would be the predominant vehicle. There is a supplemental kind of role I think that the private sector can play. I think there is no question that any benefit that may be provided as a public benefit is not going to be full dollar coverage. There are probably going to be some deductibles. There is probably going to be some coinsurance. You're probably going to place those limits if, for no other reason, because you want to prevent this potential woodwork effect that some people have been concerned about.

So, you're going to want people to be careful about selecting a particular benefit and think very prudently about it. I think a good number of people may want the full coverage and it might be very appropriate for the private sector to fill in those gaps. I think that the public sector is going to have to be relied upon to be the primary vehicle and the public sector certainly is going to have to be depended upon, with respect to those gaps, to deal with those gaps for the lower and moderate income persons as well.

Commissioner **Davis**. I ask Mr. Gehring, do you feel that the private sector should play a significant, if not predominant, role?

Mr. **Gehring**. I don't believe that the insurance industry can provide a major impact on this problem. I say this because it is predominantly a middle class problem. Well-to-do people can take care of their needs. There is already some form of assistance for impoverished people. It is that broad group of people in the middle class that have no protection today.

Through private insurance, the upper range of the middle class might be encouraged to have enforced savings that would give them protection. I don't think it would be broad-based enough to reach most of the families that are potential for being affected.

Mr. **Pollack**. Mr. Davis, I just want to differentiate, if I may. What I think distinguishes long-term care insurance from other private sector insurance plans, like automobile insurance or homeowner's insurance, is the inherent difference between those different products.

With respect to long-term care insurance, I think that by and large, the people who are interested in purchasing long-term care insurance are those people who believe they have some fairly high likelihood that they're going to need it.

Contrast that with homeowner's insurance, which almost everybody buys—even though you don't necessarily expect a fire. But by and large, everybody gets homeowner's insurance. The same would be true with automobile insurance.

Commissioner Davis. Right, but I gather that both of you feel that the private sector must participate in this—that it should not all be the public sector.

Mr. Pollack. Absolutely.

Commissioner Davis. You came down against the private sector. I just wanted to hear you say that we have to have a combination of both, if that is what you've said.

Mr. Pollack. Yes; that is what I said. The point I wanted to make in terms of why it is difficult to rely on the private sector as the predominant vehicle is that if the people who are purchasing long-term care insurance are those who, in effect, self-select because there is a fairly high predictability that they're going to need it, then insurance companies are going to have to naturally do certain things to protect themselves, so that they don't go bankrupt.

It means they're going to have to charge higher premiums. They're going to have to exclude people from coverage who have the highest predictability of needing the long-term care coverage and if we spread the risk, as the public sector I think can do to the entire population, then I think we can provide long-term care coverage for everyone at a manageable cost. Spreading that risk to the entire population is much more difficult for the private sector to do.

Commissioner Davis. Thank you.

Chairman Rockefeller. Bill Gradison?

Representative Gradison. Thank you, Mr. Chairman. I would appreciate it if any of the witnesses who care to would comment on the question of whether there should be some degree of testing of financial needs and financial resources in the programs which you are advocating.

About 1 year ago, the House of Representatives considered and rejected a very dramatic expansion of home health care benefits, a proposal laid before us by the late Claude Pepper. It was an important entitlement program that helped fill a gap that each of you has spoken about.

It is always difficult to tell why a measure is approved or not approved, but I had a lot of members come up to me afterward and say that they didn't think that the Government had a responsibility to help Donald Trump pay for long-term care at home if he happens to need it at some time in the future.

So, the question of how you feel about needs-testing is important as we consider the alternatives. Any comment?

Ms. Glasse. Yes, if I may, please. People in this country do not look positively on welfare services. And people on welfare feel demeaned. Once we base eligibility upon financial need, that service becomes a welfare program. Having led, designed, and administered many programs, I know how much the elderly resist participating in any programs that smack, in any way, of being welfare.

This long-term care need is so widespread, so pervasive, that, I believe, it must be an entitlement. The Older Women's League realizes that deductibles and copayments are going to be inevitable, and that it's going to need to be a broad-based insurance program, too.

I think to turn it into a welfare program is one that would be very unwise and would be distasteful for older people of this country.

Mr. **Pollack**. Mr. Gradison, I'd like to take a shot at the question that you raised. I don't think I'm going to give you a black and white response to that. The first thing worthy of note is when you consider which are perhaps the most popular domestic programs that we have right now—clearly, Social Security and Medicare always come up very high on the charts. I think the reason Social Security and Medicare are so popular is because there is a feeling of community participation. Everyone on some level participates. Everyone on some level pays. Everyone on some level receives benefits.

However, it is interesting that both Social Security and Medicare do have some sensitivity about the means of those people who are participating. Social Security, for example, does take better care of those with lower incomes than it does for those with higher incomes. It does that through the bend points. I don't think people have been very upset about the way the Social Security Program is structured. Yet, it does provide more assistance to those people who need it the most.

One of the things that you achieved that you should be proud of having achieved, despite difficulties you experienced yesterday, was that in the Medicare catastrophic legislation with the piece that survives there is a kind of a wraparound protection for the people who need it the most.

The Medicaid Program is wrapping around the Medicare Program so that the premiums, deductibles, and coinsurance are picked up for those people who can't afford them.

What we want is something that has everyone involved at some level paying and receiving, but that provides some special protections for people who need them the most. Then you get to the question of benefits and then you get to the question of financing. Obviously I can't imagine that members of this panel are going to repudiate progressive financing. It's been a cardinal principle in our taxation system, although it has been violated in the last week in a bunch of different ways.

Representative **Gradison**. Well, frankly, not to argue with you too much, but neither of the two programs which you cite as being the most popular programs around, Social Security and Medicare, has been financed on a particularly progressive basis.

You know, if the logic is that we should borrow from those, we would end up with payroll tax—a source of financing—it's more proportional than progressive, but some progressivity in the benefit schedule.

Mr. **Pollack**. I was focusing predominantly on the benefit side. With respect to the financing, I think the difficulties that we had with respect to the catastrophic legislation was we had two things happening at the exact same time. We had one generation financing and we had means-testing. I think it was those two unique things happening for the first time that caused the problem. If we truly consider this to be a family benefit, we won't have one generation financing because everyone in the family will have a stake in it. Then if we establish a progressive financing system, it won't take such a bite out of those people who've got the burden of paying the taxes of it.

Chairman **Rockefeller**. I'll ask the final question for this——

Mr. **DeGeorge**. Could I respond to the question as well.

Chairman **Rockefeller**. Yes.

Mr. **DeGeorge**. Mr. Gradison, there is only one Donald Trump in the United States, and there are 290 million Americans who need long-term health care or will need long-term health care. Regarding means-testing, many of the people that apply for certain programs and become means-tested, are the very people that are being denied care in other areas because of the eligibility for certain programs and the limitation that it puts on them not to qualify for other programs. That's part of the problem.

In the meantime, while I have witnessed over the years that some families who are means-tested and their total family income is counted for certain programs, that that family will not allow their younger family members to go become employed, go seek health and education for their own welfare, and then maybe end up becoming welfare recipients throughout their lifetime.

So, it becomes self-perpetuating if you really look into the programs. That is another one of the problems. That's my response to your very well put question.

Chairman **Rockefeller**. One final question to Mr. Gehring. You pointed out that it really isn't fair to gauge what is happening or has happened to catastrophic—the bill—because of public opinion polls, et cetera. You also say that long-term care wasn't provided in that legislation and that is what seniors really want. I remember 3 years ago in West Virginia—at all the senior forums that I held—there were two things that people were talking about.

One was the fear of being struck down by some disease and actually going into bankruptcy in order to qualify for Medicaid. That was an overwhelming fear. The other was prescription drugs. Seniors wanted prescription drug coverage. Indeed, the Medicare Catastrophic Act includes prescription drugs.

In that bill, Mr. Gehring, there is long-term care and there is protection against impoverishment for individuals with spouses in a nursing home. Under Medicare Catastrophic, more nursing home days are covered, not radically more but substantially more. There is a respite benefit which, in my judgment, is an important benefit for families needing assistance taking care of a spouse or a parent. So the question I would ask you is, do you think it really was misunderstanding that caused the reaction on the part of so many seniors—or do you think it is the financing that most seniors object to? As you know, the mandate that we had from President Reagan was that it be self-financed.

If catastrophic is repealed, we'll probably have a Gramm-Rudman sequester, that will be devastating to the budget, financial markets—and others that look at us, will be awestruck by our inability to manage our affairs.

What do you think was the basic reason for the protests against that bill?

Mr. **Gehring**. Well, first of all, I would like to agree with you that there are some things in that bill that certainly benefit seniors and are worthy of their support. I think, and this is a personal opinion, we as an association have not addressed the catastrophic bill, is that it was regarded as half a loaf with respect to the major risk which is the very problem we're addressing today, long-term care.

I suggest there might be another nuance to the funding aspect. You've all heard that a lot of the opposition was perceived as being from people who, for the first time, were singled out as an age group to bear the full burden of the cost. Not only was this a selected age group, but they probably, because they are the more well-to-do people or they wouldn't have to pay the taxes and have the surcharge, already have some form of catastrophic private insurance.

Do you understand what I'm saying.

Chairman ROCKEFELLER. I do. Lou, do you want to answer?

Ms. GLASSE. If I may, very briefly, sir. The Catastrophic Care Act provided minimal respite care and expanded nursing home care. The nursing home care expansion was only for skilled nursing needs. These do not meet the needs of most frail older people. Long-term care services for the chronically ill including the socially oriented custodial care services is needed most.

Respite care—the act called for 80 hours a year, or 5 hours a month, or 1¼ hours every week—that is not enough to even go to the grocery store and back. That is so minimal, and insufficient that people didn't perceive this provision as being a real benefit.

Second, I was shocked at the anger of older people to the Catastrophic Care Act. I think that part of the reason was that the act was being considered at the same time as the savings and loan "bailout." Many saw this as giving to a group of greedy business people who have cost this country so much money, whereas older people have continued to pay their share and support the country. They felt that this Catastrophic Care Act user tax was unfair.

Chairman ROCKEFELLER. I thank all of you very much for your patience and for your contributions to help us in our difficult deliberations.

Senator DURENBERGER. Can I ask a question?

Chairman ROCKEFELLER. Yes, Dave.

Senator DURENBERGER. I think the Senators, at least, are going to disappear for a little while because we've got three straight votes. I would like to stimulate you to go back and perhaps amend your written presentation a little bit if you'll take the time, just to try to respond to about four important issues that I think we're going to have to deal with. One you have already addressed in the other question and that's the whole issue of progressivity.

I think, unfortunately, in the question that you got on it, it was addressed in terms of needs-testing so it got a welfare response. I can understand why phrased that way, it gets a welfare response. It seems to me that we must deal with the issue of progressivity in the receipt of benefits in the social insurance and related systems somehow or we'll never make it. We're not going to make it unless we come to grips with the issue of progressivity.

We have it in the receipt of practically all other benefits. If you work for a great big company that has first dollar health insurance coverage, you get three times as much benefit as if you're some poor guy working in a small business someplace that can't afford health insurance or, if they can, they pay twice as much for it and it's paid with after-tax dollars.

So, you can go anywhere else other than the social insurance system and you see some existing progressivity, some of it unfair, some of it fair. So, I would really like to see all four of you give us some advice on the issue of progress, how we can do progressivity in the receipt of benefits in a better way than we did with that supplemental premium on catastrophic.

Related to that, is the role of private insurance and so forth. What I'm curious to know is whether or not there is anything to be learned from the existing way in which the private insurance market protects the elderly and disabled against out-of-pocket expenses for medical insurance. It strikes me that most elderly, between Medicare, retiree health benefits and supplemental—are paying much more than they should to insure themselves, because they don't even know what, in many cases, they're insuring themselves against.

Maybe we can learn something about how to because I agree with everything that's been said here. We have to have this private insurance market. It helps us save and do a lot of things. How might we do it better on long-term care learning from our experience on medical?

The second point that I would hope you would address is the issue of generational equity. Again, a lot of confusion around catastrophic when we said this is going to beneficiary, and somehow we're going to break the link with intergenerational transfers. I don't think there is anybody here that believes that that is what we should do, particularly with regard to the long-term care.

Right now, long-term care is the ultimate in intergenerational system. It isn't fair to shift the whole burden for long-term care, even the SNF [skilled nursing facility] benefits we put, to the beneficiaries, because then that relieves their children and their grandchildren of a huge burden and it is inappropriate to do that and just say that from now on, the elderly are going to have to pay for their own benefits, I don't think makes a whole lot of sense. There is a place for this generational equity in the way each generation shares some part of the burden.

To the degree that you can help us think about that as we move into major long-term care programs, where should we say clearly this is intergenerational? The benefits are to the children, and the grandchildren, therefore, as you change the program, it is OK to pass some of that cost back down the line.

Certain things ought to be with the beneficiary. I opt to save and then get rewarded for my savings by being able to convert some of my savings into long-term care insurance or into nursing home or home health care. So, you can't relieve me totally of the responsibility for long-term care, or I won't bother to save and put any money away. I won't bother to buy insurance. I think we need help on that.

The third is the issue of cost containment. You can't go into this program unless we find a better way to control the costs of these programs. Again, health insurance is instructive. If there is no responsibility on the person who utilizes the system, you end up with a $550 billion a year, 12 percent of GNP, medical system. We can't do that in long-term care or we're going to hurt the people that need the long-term care.

We need some advice from you on how to keep family, and the individual involved in the cost so that somehow or other we maintain the current benefits. There is a lot of cost containment when you're kids or your spouse are taking care of you. You're finding ways to hold down the costs and do things better. We transfer this whole thing over to the Government or the social insurance system, we lose that element of cost containment.

The fourth and the last one is the most difficult, that is the issue of quality. How much of the current cost of this system are the way we try to do quality control? You've got to have four of this, six of that, a whole bunch of paper—all the rest of this stuff. Not a very good way to measure what we expect in quality or outcomes from this system.

So those of you who have dealt so long with these issues like—the folks at Alzheimers, and so forth, I think it would be very beneficial in our deliberations if you can help us think in terms of how can we, as a society, measure quality and outcomes differently from the very expensive way we have been doing it up to now? Which is to pass these quality control acts every 2 or 4 years on nursing homes and things like that.

To the extent that each of you can help the record and help all of us come to grips, don't you think Mr. Chairman, with this issue of quality or outcomes, or whatever we might call it, I think that would be extremely helpful. I regret taking this much time, but I just learned from all the questions of my colleagues what I should ask.

I think those are four big things we're going to have to wrestle with here as we come to our recommendations, and I know from your testimony and your work in the private sector, all of you, that you're the ones that can help us. Thank you, Mr. Chairman.

Chairman ROCKEFELLER. Thank you. Dave and I have to go vote. We have three consecutive votes. Bill Gradison will be chairing until I return. Panel 2 consists of Charles Kelly, from the National Alliance for the Mentally Ill on behalf of the Mental Health Coalition; Martha McSteen, president, National Committee to Preserve Social Security and Medicare; Jean McGuire, executive director, AIDS Action Council; and Carolyn Zollar, National Association of Rehabilitation Facilities, on behalf of the National Rehabilitation Coalition.

Please come forward. We look forward to your testimony. Several of us will shortly return.

Representative GRADISON. Mr. Kelly, would you go first please?

STATEMENT OF CHARLES O. KELLY, ANDERSON, IN; FAMILY MEMBER, NATIONAL ALLIANCE FOR THE MENTALLY ILL, ON BEHALF OF THE MENTAL HEALTH COALITION

Mr. KELLY. Thank you. Mr. Chairman, distinguished members of the Pepper Commission, I am Charles Kelly of Anderson, IN. I am appearing here today on behalf of the seven national organizations you have listed. I am one of the 70,000 families who are members of the National Alliance for the Mentally Ill. I am grateful for this opportunity to share my personal experience with you, hoping it will illustrate some of the long-term care problems facing persons with mental illness, and their caregivers.

This time next week my wife and I will have been married 49 years. We were married in a private ceremony on a Saturday morning. When I went to pick her up, I found out she had been crying all night the night before.

When a girl cries all night before her marriage, you know there is something wrong somewhere. We didn't know what was really the problem, but we were married about 5 or 6 weeks and she was crying again. She was confused about many things.

I had the family doctor out at the house about three times. She would get a little better. Then she would get bad again. That was in October 1940. Early in 1941, I took her to a clinic in Indiana about 60 miles away. We had to go on a bus on a Saturday afternoon. They admitted her and the following Monday they took her through the clinic and gave her an examination and on the next day, Tuesday, of that week, they recommended I take her to a State mental hospital.

I called her mother. As the saying goes, she "hit the ceiling" and said: "Bring her to my house." We took her to her mother's home. We had to feed her. She couldn't take care of herself. I put food on her spoon, put it in her mouth, and it would roll out on her dress. She finally recovered. Without a lot of help, she did recover. We purchased a home, then Uncle Sam called me into service. In the fall of 1944, she got sick again.

The medical officer on the base where I was stationed (Fort Hancock, NJ) put her in the psychiatric ward on Ellis Island. She was there for a period of time, released, seemed to be better. I got discharged. Immediately after getting discharged, she fell apart again. I wrote the hospital. They recommended that I put her in a private sanitarium which I did—a mental sanitarium in Cincinnati, OH.

It went from there. She'd have periods of regression and then—well, first, she went into a State hospital in 1958. She has been in the hospital a total of 47 times, most all of it for mental illness. When young people get married, they look forward to a life of bliss. We were no different.

Little did we realize when she became sick that it was going to be a long-term thing. We thought we'd get over it. We thought we'd go on our merry way as many others that we knew did, but it has been repeated hospitalization. The last 8 or 9 years she has deteriorated to the point now where I have to bathe her. I put her clothes on her. I get her ready for bed every evening. She can't get herself dressed in the morning. Seldom can she get herself dressed and do it right.

It has been about 4 years now since she spent a nickel. She'll never spend another nickel. If I go to the mall or anything like that, she won't even get out and go see the Christmas lights. She wants to withdraw.

I've told you a little about my story and I'd like to take a few moments to summarize some key points in the written testimony I have here that mental disorders may result in serious functional impairments which prevent persons from living independently in their communities. The assessment of the long-term care services should focus on the ability to function independently.

There are many instances where activities of daily living will not appropriately measure a person's ability to function without assistance. We need an assessment tool which is broad enough to address the unique circumstances of functional disability related to mental disorders.

Eligibility criteria for long-term care services must adequately assess the functional impairments caused by the full range of mental disorders. Persons with disabilities, whether physical or mental, may beat varying levels of functional incapacity regardless of their age.

As your Commission proceeds through its work, we urge you to recognize the intergenerational aspects of long-term care, both from the standpoint of the person with the functional impairment and from the standpoint of the caregiver.

In our view, the functional impairment and disability standard which is most appropriate is that which is not limited by age or diagnostic category. We are convinced that the number of prospective beneficiaries will remain relatively small. We believe that respite care should be an integral part of any national long-term care strategy, as an estimate two-thirds of persons with mental illness are cared for at home by relatives, often parents and spouses.

If their caregiving role is not supported, it will increasingly be relinquished to the public sector by the necessity of the age and competing home demands. The cosponsors of this testimony believe, as I do, that the unequal treatment of mental disorders by insurance carriers must not be carried over into long-term care proposals.

Service providers under any long-term care proposal, should include those that are appropriate for individuals. I thank you for allowing me to testify today and would be happy to answer any questions.

[The prepared statement of Mr. Kelly follows:]

TESTIMONY OF

THE AMERICAN PSYCHIATRIC ASSOCIATION
THE AMERICAN PSYCHOLOGICAL ASSOCIATION
THE MENTAL HEALTH LAW PROJECT
THE NATIONAL ALLIANCE OF THE MENTALLY ILL
THE NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM DIRECTORS
THE NATIONAL COUNCIL OF COMMUNITY MENTAL HEALTH CENTERS
THE NATIONAL MENTAL HEALTH ASSOCIATION

Presented by

Charles Kelly, Family Member of the National Alliance
of the Mentally Ill

before the

PEPPER COMMISSION

on the subject of

THE LONG-TERM CARE NEEDS OF INDIVIDUALS
WHO ARE FUNCTIONALLY IMPAIRED BY MENTAL DISORDERS

October 5, 1989

Mr. Chairman and honored commissioners, I am Charles Kelly, a family member of the National Alliance for the Mentally Ill (NAMI). In addition to NAMI, I am pleased to present this testimony on behalf of:

The American Psychiatric Association
The American Psychological Association
The Mental Health Law Project
The National Association of State Mental Health Program Directors
The National Council of Community Mental Health Centers
The National Mental Health Association

The testimony reflects the general position of the Associations listed above. Individual associations may also submit separate statements addressing more specific issues.

INTRODUCTION

As the Pepper Commission considers options for solving the long-term care crisis facing American families, the mental health community hopes that you will not ignore people who are functionally impaired by mental disorders, both the elderly and those under 65. Mental disorders which may result in functional impairment include behavioral disorders, affective disorders, schizophrenia, other severe mental illness, and cognitive disorders such as Alzheimers disease and other dementias.

Because of deficiencies in insurance coverage for basic mental health care, the need for long-term care for those with mental disorders is perhaps even more urgent than for those whose functional impairment is caused by a physical problem. Long-term care for the functionally impaired is generally considered in a framework that assumes coverage for basic health services and the ongoing treatment of the cause of the functional impairment. For individuals whose functional impairment results from physical conditions, e.g. diabetes or a stroke, long-term care is an additional service--one that will contribute to the continuity of their care and which will assist them to maintain their independence despite their chronic health condition.

This is often not the case, however, for those who are functionally impaired by mental disorders. Many persons with chronic mental disorders--specifically mental illness--do not receive the necessary ongoing treatment required for a chronic condition. This lack of treatment is the result of differential coverage for mental and physical disorders in both public and private insurance programs--both for the elderly and for those under 65. As a result, mentally ill persons who are marginally functional, and those who are functional only when they are receiving mental health treatment, are often rendered functionally impaired.

While the issue of differential coverage of mental disorders will be more fully discussed in testimony before the Commission on the uninsured and underinsured populations, our testimony today also addresses this issue for two reasons. First, these limitations affect the extent of the need for long-term care services among those with severe mental disorders. Second, we want to emphasize the inequitable treatment of patients with severe mental disorders under current insurance programs so the Commission is aware of the need to avoid this inequity in any proposed solutions to address the long-term care crisis facing American families.

Our testimony is divided into the following sections:

- the long-term care needs of patients who are functionally impaired by mental disorders,
- the need for appropriate measures of functional impairment,
- a description of the size and composition of the population who are functionally impaired by mental disorders,
- a summary of current programs providing long-term care services to individuals who are disabled by mental disorders,
- a brief summary of the differential treatment of mental disorders under current public and private insurance programs, and
- proposed solutions for serving the long-term care needs of persons who are functionally impaired by mental disorders.

THE NEED FOR LONG-TERM CARE FOR PERSONS WHO ARE FUNCTIONALLY IMPAIRED BY MENTAL DISORDERS

As mentioned above, severe mental disorders may result in functional impairment. Most of the long-term care bills introduced in the 100th and 101st Congress have specified Activities of Daily Living (ADLs) as the measure of functional impairment to determine eligibility for long-term care services. However, all but one of these bills have restricted the definition of eligible functional impairment to individuals who are unable to perform ADLs due to a physical or—in some bills—a cognitive impairment. Some bills have included additional eligibility criteria for those whose functional impairment is not measured by ADLs, but limit the use of this additional criteria to individuals with cognitive impairments. As a result of these restrictions, individuals who are functionally disabled by non-cognitive mental disorders have been consistently excluded from coverage.

It is our belief that the etiology of functional impairment is relevant only when determining appropriate treatment and service needs. For example, among the elderly, symptoms of both dementia and affective disorders may be caused by physical conditions and are potentially reversible with treatment. Similarly, persons who are functionally impaired by clinical depression or other serious mental illness may be able to function independently once treatment is initiated. However, there are instances where, despite treatment, individuals are functionally impaired by a chronic, severely disabling mental disorder. These individuals often require long-term care very similar to that needed by the cognitively impaired. Thus, there is no valid reason to exclude from long-term care coverage, those persons whose functional impairment is due to a severe mental disorder.

The Need for Appropriate Measures of Functional Impairment

In order to determine eligibility for long-term care services, it is necessary to have meaningful indicators of functional impairment. Because the majority (86%) of those 65 and older have one or more chronic health conditions, the presence or absence of a disease, or of a physical or mental impairment, is generally not considered a useful measure to determine the need for long-term care services. Similarly, specific medical diagnoses, by themselves, are not always useful in determining functional status. Rather, the assessment of the need for long-term care services should focus on the ability to function independently.

A person may be physically or mentally impaired but is not necessarily _functionally_ impaired. Additionally, functional impairment may not always result in disability. In many instances, functional impairment can be easily compensated for, the most obvious example being the use of wheelchairs and other mechanical devices which enable those with mobility impairments to function independently. However, there are many functional impairments which cannot be compensated for without human assistance. Such impairments have myriad causes and vary considerably in level of severity.

As mentioned, the measure that is increasingly being used to identify the impaired elderly population is Activities of Daily Living (ADLs). The majority of research in the area of disability among the elderly has used some measure of ADLs to assess functional impairment. This research indicates that the ADL scale is sensitive to changes in functional status, and as such, is predictive of the need for long-term care services. In some instances, the ADL scale can adequately measure functional impairment resulting from both physical and mental conditions. For example, a person whose right side is paralyzed following a stroke is generally unable to perform three or more ADLs without human assistance. Similarly, individuals with severe mental disorders--cognitive, affective or behavioral--will sometimes be unable to perform three or more ADLs. "Unable" is used not only in its physical sense but in its functional sense as well. For example, persons with catatonic schizophrenia may have the motor ability to perform ADLs but are in effect "paralyzed" by their mental condition. A recent study by the Rand Corporation found that people who suffer from _clinical_ depression are at least as physically impaired as those with chronic physical illnesses.

In other instances, individuals impaired by mental disorders may be able to perform ADLs, but may need cueing or supervision to do so consistently or safely.

However, there are many instances when the ADL scale will not adequately measure a person's ability to function without assistance. There are several activities which a person must perform in order to live independently. These have been termed "Instrumental Activities of Daily Living" (IADLs) and include such things as taking medicine, shopping for food and meal preparation. Many individuals with cognitive impairments and severe mental disorders may be unable to perform several of these IADLs. Recognizing the importance of these measures in assessing the need for long-term care services, the Channeling Demonstration Project used a combination of ADLs and IADLs to determine eligibility for long-term care services. The Massachusetts Home Care Program also uses a combination of ADLs and IADLs to determine the need for services and considers both physical, cognitive and _emotional_ factors in determining functional impairment (see Attachment A). Behavioral problems (e.g. wandering, physical abusiveness to self or others) may also seriously compromise a person's ability to function independently in the community without constant supervision. The relationship of these factors to functional impairment is clear when we consider that behavioral and cognitive problems (as measured by IADLs) are frequently the cause of admission to long-term care facilities.

Finally, mental health and physical health are strongly interrelated and are often interactive. Mental disorders can seriously compromise physical health and physical health problems can cause mental disorders. The interaction between mental disorders and physical illness in the elderly--particularly as it affects functioning--is only beginning to be understood well, and is the focus of ongoing research. Thus, distinctions in legislative language between physical and mental impairments, and between categories of mental impairment, in many cases may be impossible to make at the point of assessment.

For example, the physical impairment associated with clinical depression can lead to nutritional neglect which can exacerbate existing health problems. Depression associated with strokes is extremely common and can severely impair an individual's motivation to participate in a rehabilitation program, thus increasing the likelihood of severe functional impairment. A recent study of three thousand adults, age fifty-five and over, found that after controlling for age, sex, and physical health, the odds of dying were more than four times greater for individuals with affective disorders (major depressive disorders) than for others in the sample. Finally, with increasing age, comorbidity is common and many of this population will be functionally impaired by both physical and mental disorders. All of these factors underscore the importance of using eligibility criteria that adequately assess functional impairment caused by the full range of mental disorders--not just cognitive disorders.

Composition and Size of the Elderly Population

The elderly population with mental disorders who require long-term care is a heterogeneous one but may be grouped into three broad categories. The three groups are:

- individuals with a history of chronic impairment,
- individuals who develop a mental disorder in later life with no prior history of impairment, and
- individuals with mental disorders associated with physical health disorders, often occurring in later life.

Estimates indicate that between three and five million of our nation's elderly have significant mental health problems. This figure includes a large proportion of persons who have various types of dementias, some reversible. Because these data are highly aggregated, they do not reveal major differences in the type, severity and duration of mental health problems. Some mental health problems may be situational and short-lived, resolving themselves with or without treatment. In the case of severe non-cognitive mental disorders, some individuals may have frequent acute episodes of a chronic disorder, intermittent acute disorders, or stable chronic disorders. Thus, these data provide little insight into the size of the population who are functionally impaired by chronic non-cognitive mental disorders.

Unfortunately, there are limited data with which to estimate the size of this population. However, the data that do exist suggest that, compared to the population that is functionally impaired by physical and cognitive disorders, this population is relatively small.

Using data from the National Long Term Care Surveys in 1982 and 1984, analysts at the National Center for Health Statistics estimated that out of 4.1 million persons who had two or more ADL limitations, fewer than 50,000 were impaired due primarily or solely to a mental disorder other than dementia or other cognitive impairments.

Information from the Canadian long-term care system also points to the the relatively small number of persons who are functionally impaired due solely to non-cognitive mental disorders. In British Columbia, a province with a population of approximately 3 million, the long-term care system serves the needs of all individuals who are functionally impaired, regardless of age or the cause of impairment. Out of approximately 25,000 elderly receiving services in long-term care facilities, an estimated four percent are functionally impaired solely by non-cognitive mental disorders. About half of these individuals are cared for in the Residential Mental Health Program, and the remainder are in long-term care nursing facilities.

The Population Under 65

Many long-term care proposals focus on services for the over 65 population but those under 65 also need long-term care. In 1986, 20 percent of 2.7 million disabled workers receiving Social Security Disability Insurance (SSDI) benefits were suffering from mental disorders other than mental retardation. The percentage is even higher--36 percent--for SSDI recipients under 40. Approximately two thirds of adults with mental disorders are cared for at home by aging or aged parents.

Since there is no precise definition of what constitutes a "long-term" mental disorder in children, it is difficult to estimate the number of children under 18 who have such disorders. Additionally, there is a lack of age-appropriate measures of functional impairment for this group. Much more research is needed to determine the type and level of functional impairment caused by severe mental disorders among this population. It is important that solutions to the long-term care crisis not neglect the needs of these children and their families.

Current Long-Term Care Services For Persons With Chronic Mental Disorders

With a few important differences, the long-term care service needs of the functionally impaired population with severe non-cognitive mental disorders are in many cases similar to the needs of the population functionally impaired by dementia, Alzheimers disease, and related cognitive disorders.

Home and Community Based Services

There are a wide range of long-term care services that may be offered through the Medicaid program. For example, in 1987, several states provided Medicaid financed services to persons who were functionally impaired by mental disorders through the Rehabilitation Services option.

Services provided under the Medicaid Rehabilitation Option must be recommended by a physician or other licensed mental health practitioner within the scope of their practice under state law. The services must be aimed at reducing physical or mental disability and restoring the indvidual to the highest possible level of functioning. These services frequently include day programs and medication management programs. The purpose of these services is to help recipients develop and maintain necessary community and daily living skills, including personal hygiene and grooming, meal preparation, and other instrumental activities of daily living. Many states offer similar services through the Medicaid Clinical Services Option, since clinic services may include palliative and rehabilitative services as well as preventive and therapeutic services.

Other long-term care services for functionally impaired persons with mental disorders may be offered through the 2176 Waiver Program. Services may include case management services, respite services, habilitation programs and day care. Only Vermont is currently operating a waiver program specifically targeted at persons with mental illness. However, other states also serve this population through programs which serve a broader group of disabled individuals. In addition to the Medicaid program, some states also have their own long-term care programs, some of which serve persons functionally impaired by mental illness.

Nursing Home Care

The Institution of Medicine report, Improving the Quality of Care in Nursing Homes, estimated that a significant portion of the nation's nursing home population (between 50% and 60%) have some type of mental or behavioral disorder. The vast majority of these persons have senile dementia or related disorders. The report estimated that roughly 72,000 nursing home residents have a diagnosis of mental illness either solely or in conjunction with other disorders.

In response to the IOM study, Congress included nursing home reform provisions in its Omnibus Budget Reconciliation Act of 1987. Among the many purposes of OBRA '87, as enacted, are two specific to the area of mental health: (1) to prevent the inappropriate placement of persons with mental illness in Medicaid certified nursing facilities through the use of a preadmission screening and annual resident review process (PASARR) and (2) to provide necessary mental health services to persons who are appropriately placed in Medicaid certified nursing facilities.

OBRA '87 provides the framework to address the role of nursing homes in meeting the long-term care needs of persons with mental illness. If the law is implemented as written and intended,

1. the inappropriate placement of persons with mental illness seeking admission to a Medicaid certified nursing facility will cease;
2. persons with mental illness inappropriately placed in nursing facilities as of December 31, 1988 will be transferred to appropriate alternative settings;
3. persons with mental illness who are appropriately placed in nursing facilities will have their mental and psychosocial, as well as their physical needs met; and
4. persons appropriately placed in nursing facilities who require psychoactive medications, neuroleptic drugs or psychotropic drugs will receive medication management within a comprehensive treatment plan with proper professional consultation oversight.

However, even if OBRA 87 is fully implemented as written and intended, significant problems remain:

1. Persons seeking admission to a Medicaid certified nursing facility who are assessed as not requiring nursing facility placement are not specifically addressed through OBRA '87 Medicaid provisions. Such persons will continue to depend on the availability of mental health services and long-term care services for persons with mental illness offered in the states and communities in which they reside. In many states, these services

are inadequate for their needs. As a result, a large number of these persons may become more functionally impaired.

2. Nursing facilities which provide the mental and psychosocial services required by appropriately placed persons as specified by OBRA '87, risk being reclassified as Institutions for Mental Diseases (IMDs), and as a result, may lose Medicaid reimbursement since only 24 states offer IMD services as a Medicaid option.

Thus, while OBRA '87 significantly addressed the role of nursing homes in meeting the long-term care needs of persons with mental illness, substantial problems will remain, even if fully implemented.

PROPOSED SOLUTIONS

We are greatly concerned that the differential treatment of mental disorders in current insurance coverage not be carried over into long-term care proposals. Both the Medicare and Medicaid programs have limitations on coverage for patients with mental disorders. In the Medicare program, these limitations include both an annual cap of $1,100 on most outpatient services, exclusion of organized outpatient care settings from coverage, and a lifetime limitation of 190 days for inpatient treatment. For outpatient services there are significantly higher beneficiary copayments required than for treatment of physical disorders.

Under the Medicaid program while services must be available to the mentally ill on the on the same basis as for all other Medicaid recipients, statutory exemptions and the optional nature of many benefits, results in a large number of patients not receiving the services they need. Limitations include the exclusion of reimbursement for psychiatric inpatient care for mentally ill individuals between ages 22 and 64, prior authorization requirements, restrictions on the number of allowable visits, high copayments and special rate limits. As a result, provider participation in the program is limited and uniform mental health coverage under Medicaid does not exist.

Data from the Bureau of Labor Statistics (1986) indicate that few persons with mental disorders have equivalent coverage for both mental disorders and physical disorders. Only 37 percent of insured persons have equivalent coverage for inpatient care (a drop of approximately 20 percent from the 1983 survey), and only 6 percent have coverage for outpatient services equivalent to that for physical disorders. Limitations on coverage are also evidenced by higher copayments for mental health benefits, and day, visit and dollar limitations on reimbursement.

As noted earlier, this differential coverage may contribute to the prevalence of functional impairment among persons with mental disorders since they may be able to function independently only if they are receiving adequate treatment. For the population who, despite treatment, are functionally impaired by non-cognitive mental disorders, there is ample evidence, from programs in this country and in Canada, that the long-term care needs of this population are equivalent to those of the population disabled by physical and cognitive conditions and can be met by appropriately designed programs. A 1982 study by the U.S. General Accounting Office, The Elderly in Need of Mental Health Services, found that many of the services which the mentally at-risk elderly need are social supports, rather than, or in addition to more traditional mental health interventions. Recognizing this need and the feasibility of providing such services, we would like to make the following recommendations to the Commission.

Public Sector Proposals

We strongly recommend that just as functional impairment is the sole criterion for determining eligibility for long-term care services for individuals with physical or cognitive impairments, it should also be the sole criterion for individuals with non-cognitive mental impairments. Since the etiology of a disorder is not considered relevant when determining eligibility for acute health care services, neither is it relevant when determining eligibility for long-term care services. Excluding individuals whose functional impairment is due to a non-cognitive mental disorder is analogous to refusing to cover acute care for persons with gastrointestinal ulcers or ulcerative colitis when those conditions are exacerbated or caused by severe anxiety, which they often are. Such distinctions are unacceptable in acute care policy and are equally unacceptable in long-term care policy.

In order to insure coverage of all persons in need of long-term care, measures of functional impairment must not be so restrictive that persons with mental disorders are excluded from coverage, particularly persons with non-cognitive mental disorders. The legislative language we suggest is that, "Eligible individuals include those who are unable to perform, without human assistance, two or more activities of daily living or who have a similar level of disability due to a mental disorder." Appropriate measures of a "similar level of disability" should be determined by the Secretary.

The services included in any long-term care proposal should include those that are appropriate for individuals disabled by mental disorders. They would include all those services currently offered under the various Medicaid options and the 2176 Waiver program. Additionally, transportation services to and from day programs are essential, particularly in rural areas.

Private Sector Proposals

There have been several bills introduced in the 100th and 101st Congress which have sought to promote the purchase of private long-term care insurance as a solution to the long-term care crisis. While there are many concerns regarding the ability of the private sector to meet the long-term care needs of the majority of the U.S. population, our particular concern relates to policy restrictions and underwriting practices which may exclude persons from coverage even if they can afford to purchase insurance.

The National Association of Insurance Commissioners (NAIC) model long-term care policy regulation excludes individuals who are impaired by mental disorders other than Alzheimers disease and related disorders. We strongly recommend that as the government seeks to promote the purchase of long-term care insurance it must also act to ensure that long-term care policies do not have discriminating eligibility provisions.

SSI Improvements

A modest proposal for addressing the long-term care needs of the elderly and disabled (regardless of the etiology of the disability) is H.R. 3203—the SSI Community Living Amendments. We strongly support the provision of this bill which would create a a federal-state matching grant program targeted to SSI eligible persons with disabilities who require regular assistance to maintain their natural residence. The additional benefit can be used to pay for personal care and other necessary long-term care services. It is important to note that the bill makes no distinction between SSI recipients who are disabled by mental disorders as compared to physical disorders.

The bill would also provide grants to states to implement much needed reform in the board and care home industry. A large proportion of mentally disabled and elderly SSI recipients currently reside in unlicensed board and care homes. A 1973 Denver Institute Report noted that of 2,933 board and care residents surveyed, 77.9 percent were mentally ill. The need to reform the board and care industry is particularly urgent since the OBRA 1987 PASARR regulations will likely result in an increase in the number of persons with disabling mental illness being cared for in such homes.

CLOSING STATEMENT

The Commission will play a major role in setting the agenda for long-term care reform. As you consider possible options we strongly urge you to be guided by a concern for equity and to address the needs of all functionally impaired persons. Persons who are functionally impaired by non-cognitive mental disorders must be included in any proposed solutions to the long-term care crisis facing American families.

We thank you for this opportunity to present our views.

ATTACHMENT A

MANAGING A LONG TERM CARE SYSTEM

Commonwealth of Massachusetts

Paul J. Lanzikos
Secretary
Exectuive Office of Elder Affairs
38 Chauncy street
Boston, Massachusetts 02111
(617) 727-7750

MASSACHUSETTS HOME CARE PROGRAM CLIENT NEEDS ASSESSMENT

Circle All That Apply:

1 — Protective Services
2 — 2176
3 — CCC
4 — Respite
5 — Congregate
6 — Cross Reference

Intake Date ____________________
Date of Assessment ____________________
Where? ____________________

Home Care Agency ____________________
Client ID # ____________________
Casemanager ____________________

FUNCTIONAL IMPAIRMENT LEVEL

Level				
Date				

KEY FACTS

1. Name ____________________
2. Address ____________________
Town/City ____________________
3. Telephone # ____________________
4. Social Security # ____________________
5. English Spoken: Yes No
Principal Language if not English: ____________________

6. Sex: 1 - Male 2 - Female
7. Date of Birth ____________________

8. Marital Status:
1 - Single
2 - Married
3 - Widowed
4 - Divorced
5 - Separated

9. Lives With: (circle one)
1 - Alone
2 - Spouse
3 - Spouse & Family
4 - Family
5 - Non-Family
6 - Family/Non-Family

10. # Clients in Household ______

11. EMERGENCY CONTACTS
a. Name ____________________
Address ____________________
Town/City ____________________
Relationship ____________________
Telephone # ____________________

b. Name ____________________
Address ____________________
Town/City ____________________
Relationship ____________________
Telephone # ____________________

c. 1 - Legal Guardian 2 - Conservator 3 - Payee:
Name ____________________

12. MEDICAL RESOURCES:
Hospital ____________________ Telephone # ____________________
CHHA ____________________ Telephone # ____________________
Primary Doctor ____________________ Telephone # ____________________
Other Doctor ____________________ Telephone # ____________________
HMO ____________________ Telephone # ____________________

13. FINANCIAL CATEGORY:
1-Medicaid
2-Basic
3-Sliding Fee Max. Fee ______
4-Respite $ ______

14. Health Care Coverage:
☐ Medicare # ____________________
1 - Part A 2 - Part B
☐ Medicaid # ____________________
☐ Medex 1 2 3 # ____________________
☐ Other ____________________

15. Source of Referral: ____________________

16. Reason for Referral: ____________________

17. Type of Response: 1 - Crisis 2 - Rapid 3 - Routine

18. Other Pertinent Key Facts: ____________________

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SECTION A: PHYSICAL HEALTH

1. Self rated health: (Circle One)
1 – Excellent 2 – Good 3 – Fair 4 – Poor

Compared to 1 year ago: (Circle One)
1 – Better 2 – Same 3 – Worse

2. Current Medical Conditions: (✓) if Diagnosed

a.	
b.	
c.	
d.	
e.	
f.	
g.	

Last MD appt. ____________ Next MD appt. ____________

Last Hospitalization: Admission Date ____________

Discharge Date ____________

# of Hospitalizations in past year ____________

3. Current Medical Treatments/Therapies:
(by self or others)

a. ____________
b. ____________
c. ____________
d. ____________

NARRATIVE: ____________

4. Current Medications:

	DATE	NAME	DOSAGE/FREQUENCY	PURPOSE	DOCTOR	PHARMACY
a.						
b.						
c.						
d.						
e.						
f.						
g.						
h.						
i.						
j.						
k.						
l.						
m.						
n.						
o.						

SECTION A: PHYSICAL HEALTH (cont)

5. Sensory/Communications:
(Check appropriate rating with aids if used)

	Good	Fair	Poor	Total Loss	List Aids
Sight					
Hearing					
Speech					

6. Dental problems? Yes No
Foot care problems? Yes No

7. Support Devices:
a. __________
b. __________
c. __________
d. __________

8. Nutrition: (Circle appropriate answer)
Special diet? Yes No
Specify__________
Being followed? Yes No
Appetite__________
Wt. change in past year__________
Daily eating habits:
Meals__________ # Snacks__________

NARRATIVE:

☐ HOME CARE INTERVENTION

SECTION B: COGNITIVE/EMOTIONAL FUNCTIONING

1. Major life changes (crises) in past year.
____
____
____
____

2. Does client appear oriented to time, place, and person? Yes No
3. Does client appear agitated? Yes No
4. Does client appear depressed? Yes No

NARRATIVE:

☐ HOME CARE INTERVENTION

COGNITIVE/EMOTIONAL MODULE: YES NO

SECTION C: ACTIVITIES OF DAILY LIVING

1 or 2 = ADL Impairment

ADL Impairments__________

Circle rating and appropriate response(s) for each ADL

	REASON: Physical	Cognitive	Emotional	WHO HELPS? Unmet Need	Formal Support	Informal Support	Home Care
	1	2	3	1	2	3	4
1:	1	2	3	1	2	3	4
2:	1	2	3	1	2	3	4
3:	1	2	3	1	2	3	4
4:	1	2	3	1	2	3	4
5:	1	2	3	1	2	3	4
6:	1	2	3	1	2	3	4
7:	1	2	3	1	2	3	4

1. BATHE
   - 0 — Independent: 1 — with device
     - 2 — with difficulty
   - 1 — Able with helper: 1 — physical assist
     - 2 — verbal cue
   - 2 — Unable
2. DRESS/UNDRESS
   - 0 — Independent: 1 — with device
     - 2 — with difficulty
   - 1 — Able with helper: 1 — physical assist
     - 2 — verbal cue
   - 2 — Unable
3. EAT
   - 0 — Independent: 1 — with device
     - 2 — with difficulty
   - 1 — Able with helper: 1 — physical assist
     - 2 — verbal cue
   - 2 — Unable
4. TOILET
   - 0 — Independent: 1 — with device
     - 2 — with difficulty
   - 1 — Able with helper: 1 — physical assist
     - 2 — verbal cue
   - 2 — Unable
5. CONTINENCE

Bladder	Bowel	
0	0	Complete Control
0	0	Self care device w/no accident
1	1	Physical assist w/device
1	1	Occasional accidents w/ or w/o device
2	2	No control despite device or physical assist

6. TRANSFER IN/OUT BED/CHAIR
   - 0 — Independent: 1 — with device
     - 2 — with difficulty
   - 1 — Able with helper: 1 — physical assist
     - 2 — verbal cue
   - 2 — Unable 1 — bedbound
7. GET AROUND INSIDE
   - 0 — Independent: 1 — with device
     - 2 — with difficulty
   - 1 — Able with helper: 1 — physical assist
     - 2 — verbal cue
   - 2 — Unable

SECTION D: INSTRUMENTAL ACTIVITIES OF DAILY LIVING

1 or 2 = IADL Impairment

IADL Impairments__________

Describe What Client Can Do

Circle rating for each IADL

1. MEAL PREPARATION
   0 Without help
   1 With some help
   2 Can't do at all

2. HOUSEWORK
   0 Without help
   1 With some help
   2 Can't do at all

#floors ____

#rooms____

3. LAUNDRY
   0 Without help
   1 With some help
   2 Can't do at all

Location: ______________

4. SHOPPING
   0 Without help
   1 With some help
   2 Can't do at all

Proximity: ______________

5. TAKING MEDICINE
   0 Without help
   1 With some help
   2 Can't do at all

6. GET AROUND OUTSIDE
   0 Without help
   1 With some help
   2 Can't do at all

7. TRANSPORTATION
   0 Without help
   1 With some help:
      1—Physical assist
      2—Access
   2 Can't do at all

Mean(s): ______________
____

8. MONEY MANAGEMENT
   0 Without help
   1 With some help
   2 Can't do at all

9. USE TELEPHONE
   0 Without help
   1 With some help
   2 Can't do at all

☐ HDM MODULE

REASON:	Physical	Cognitive	Emotional	WHO HELPS?	Unmet Need	Formal Support	Informal Support	Home Care
	1	2	3		1	2	3	4
1:	1	2	3		1	2	3	4
2:	1	2	3		1	2	3	4
3:	1	2	3		1	2	3	4
4:	1	2	3		1	2	3	4
5:	1	2	3		1	2	3	4
6:	1	2	3		1	2	3	4
7:	1	2	3		1	2	3	4
8:	1	2	3		1	2	3	4
9:	1	2	3		1	2	3	4

SECTION E: INFORMAL SUPPORTS

1. Caregiver (providing daily care)

Name____________________

Relationship____________________

2. Resides: 1 – In Household
2 – Same Building
3 – Other

3. Willingness: 1 – High
2 – Moderate
3 – Low

4. Expressing stress? Yes No

5. Relief needed by caregiver? Yes No

6. Other Caregivers:

Name	Relationship
a.	
b.	
c.	

☐ HOME CARE INTERVENTION

NARRATIVE: No Informal Caregivers ☐

RESPITE MODULE: YES NO

SECTION F: 24 HOUR SUPERVISION

1. Need for 24 Hour Supervision? Yes No

2. 1 – Long Term
2 – Short Term

3. Reason(s): 1 – Medical
2 – ADL/IADL
3 – Cognitive
4 – Emotional

NARRATIVE:

SECTION G: SOCIAL PARTICIPATION

1. Daily contact? Yes No

Type____________________
(telephone, inside, outside, mailman, etc.)

2. List groups, clubs, senior centers, church activities.

3. Satisfied with present level of socialization? Yes No

☐ HOME CARE INTERVENTION

NARRATIVE:

Representative **Gradison**. Thank you very much, Mr. Kelly. We will now here from Mrs. McSteen.

STATEMENT OF MARTHA McSTEEN, PRESIDENT, NATIONAL COMMITTEE TO PRESERVE SOCIAL SECURITY AND MEDICARE

Ms. **McSteen**. Thank you, Mr. Chairman. I am Martha McSteen, president of the National Committee to Preserve Social Security and Medicare and appreciate the opportunity to be here. Americans are counting on the Pepper Commission to put forward a realistic step-by-step blueprint that we can all follow to meet the health and long-term care needs of this country.

My testimony focuses on solutions to the long-term care problem. The national committee members fully support efforts to provide basic health care for all Americans. A logical place to begin is to increase the focus on prevention or delay of long-term care. Resources spent on finding ways to reduce the number and severity of disabilities will be worthwhile investments in the years to come.

If long-term care is implemented in incremental steps, we need to begin with a system of assessment and care management. The national network of some 680 area agencies on aging appears to be a natural location for assessment and care coordination services.

It makes sense to build on this existing system. The Nation's current long-term care policy has a strong institutional bias because the reimbursement system allows for payment for institutional care but not extensive home care. To supplement the formal system of paid home care services, a pilot program of more informal system of bartering has shown promise and could easily be expanded to local communities.

Another issue with home care is the shortage of caregivers. To encourage the continuation of this informal system, we should reimburse trained family caregivers for their efforts, or the Social Security law could be amended to provide caregivers of disabled beneficiaries the same benefits they would be eligible to receive if they had reached full retirement age.

An untapped pool of home care chore and shopping assistance is perhaps this Nation's college students. Linkages between home care providers and colleges around the country could be encouraged through work study programs or grants. Nursing homes will continue to be an essential and necessary part of our long-term care system.

In the development of new nursing home beds, we need to consider the need for a specialized bed for Alzheimer's patients, for example. Expanding coverage to long-term home care and institutional care is clearly costly and the only way to finance it is with broad-based financing.

Instead of Medicare paying a set amount for nursing home stays after a certain period, a percentage of seniors' income could be used toward the nursing home stay. In Denmark, for example, residents pay for their nursing home stay with their Social Security check and 60 percent of other income up to the full cost of the stay. A set monthly personal allowance is assured and the seniors' assets are not touched.

To protect seniors with income above the poverty line, a sliding scale could be used so that, for example, Medicaid would pay 100 percent of Medicare copayments and premiums up to 125 percent of the poverty line, but only pay 50 percent of copayments and premiums up to the 200 percent of the poverty line.

The solution avoids means-testing of Medicare benefits while still protecting the poor and the near-poor. The national committee has long advocated eliminating the wage base of Medicare payroll tax and making coverage for Medicare mandatory.

Eliminating the wage base would make the payroll tax less regressive and provide sufficient funding for long-term home care similar to that proposal made by the late Congressman Pepper.

In addition to public solutions, private solutions must be sought in terms of better, more affordable, long-term care insurance products. To encourage employers to offer long-term care insurance to employees, the Tax Code should be amended to provide tax treatment of long-term care coverage similar to that afforded health assurance and life insurance.

Another incentive is to provide for conversion of life insurance to long-term care insurance at a time when the employee's life does not have the same obligations. A third option would be to allow for a free tax conversion of assets in an IRA.

The national committee believes that a public-private solution to long-term care is necessary. Private solutions alone are not adequate and we must have the public long-term basic insurance program. It is easy to agree on the need for all services related to long-term care, but harder to find the financial resources.

The national committee pledges to work with other interested parties to provide health insurance coverage for all Americans including long-term care for people of all ages. Thank you, Mr. Chairman.

[The prepared statement of Ms. McSteen follows:]

NATIONAL COMMITTEE TO PRESERVE
SOCIAL SECURITY AND MEDICARE

2000 K Street, N.W., Suite 800, Washington, D.C. 20006 (202) 822-9459

STATEMENT OF
MARTHA McSTEEN
PRESIDENT
THE NATIONAL COMMITTEE TO PRESERVE SOCIAL SECURITY AND MEDICARE

PRESENTED TO
THE PEPPER COMMISSION

REGARDING
OPTIONS IN LONG-TERM CARE

OCTOBER 5, 1989

Mr. Chairman, I am Martha McSteen, President of the National Committee to Preserve Social Security and Medicare. Americans are counting on the Pepper Commission to put forward a realistic step-by-step blueprint that we can all follow to meet the health and long-term care needs of this country. National Committee's five million members are committed to doing everything possible to help make the Pepper Commission's work a success.

Members of the National Committee realize that the Commission's job is difficult. Meeting the health and long-term care needs of this country is an extremely complicated, controversial and costly problem. The National Committee realizes that it may take years to fully implement a program guaranteeing health and long-term care for all Americans, yet it is an imperative goal.

My testimony focuses on solutions to the catastrophic long-term care problem, although the National Committee members fully support efforts to provide basic health care for all Americans. The members understand the fear of being uninsured or underinsured. They also realize that Medicare's problems cannot be isolated from the larger health care industry in the United States. While almost all seniors have some insurance protection, health care cost escalation threatens to undermine this protection. Medicare reforms alone, however, cannot halt the cost escalation.

ACTION IS NECESSARY

Clearly, one of this country's most compelling social goals is to establish a comprehensive, coordinated policy on long-term care for all Americans. The National Committee would like to highlight two points. First, that seniors have consistently said that long-term nursing home and home care is essential. Second, that seniors are willing to pay their fair share for new benefits for all Americans.

If we do not act soon, we will be unprepared to face a severe problem a few years down the road as an increasingly larger senior population becomes frail. The Urban Institute projects that our frail senior population will grow from 2.5 million in 1984 to between 8.7 and 12 million in forty years. The same study also predicts that the number of single frail seniors -- the ones most in need of formal care-givers -- will grow disproportionately because of recent low fertility and marriage rates. Future seniors will have fewer family members to care for them in later years. The Urban Institute expects at least 30 million seniors will be living alone in 2030 as compared to 8.4 million in 1984.

These figures do not include approximately one million children with severe chronic health problems who are currently in need of ongoing care. Many such children would previously have died, but are now saved due to advances in modern medicine. A recent General Accounting Office report on families with chronically ill children found that while most families had no difficulty obtaining medical services, they do have difficulty getting support services.

Any national long-term care system should include all age groups. A chronic illness or disability is a heavy financial and emotional burden on the individual as well as the family -- no matter what the age of the victim. This burden should be eased by support from the general population based on the concept of social responsibility that this country has embraced.

WHAT KIND OF ACTION

Long-term care is more than funding. It is the tremendous task of coordinating a fragmented system of diverse services with different funding sources. The services range from transportation, shopping, chore service, meal preparation and adult day care all the way to senior housing and institutional care. Long-term care encompasses both the care and the setting of that care. We need to begin laying the groundwork for a comprehensive long-term care system which invariably will require years of fine tuning. Let's look at some of the parts.

Research and Preventive Care

A logical place to begin is to increase focus on prevention or delay of long-term care. Resources spent on finding ways to reduce the number and severity of disabilities will be worthwhile investments in years to come. For example, often it is a broken bone caused by osteoporosis that forces the senior living alone to enter a nursing home; or the final straw which causes the family to give up caring for the senior at home is the 10 loads of laundry due to incontinence. We have made progress in treating the conditions that can cause dependency, but we need more research and more education.

Assessment and Care Coordination

If long-term care is implemented in incremental steps, we need to begin with a system of assessment and care management or coordination. Frail seniors in need of community services should be assessed by a multi-disciplinary team charged with developing the best care plan. For best results, the assessment should be done in the senior's home. The home setting provides the clearest picture of the person, the aids and the obstacles to daily functioning. Care coordinators should then be responsible for carrying out the care plan by coordinating community services.

Reassessment should be done at regular intervals or when the condition has clearly changed. This is important because research indicates that "long-term care" is not necessarily "permanent care."

Many seniors move in and out of disabilities and may function quite well without formal services in between setbacks or they may move into acute care. Every effort shuld be made to create one payment system so that acute care can be integrated with long-term care.

The national network of some 680 Area Agencies on Aging is the natural location for assessement and care coordination services. Area Agencies on Aging, created 16 years ago under the Older Americans Act, are already providing, or subcontracting for, care coordination in more than twenty-five states. It makes sense to build on this existing system and to strengthen the agencies that are less developed. These agencies are intimately familiar with available community services; they have years of experience with linking and coordinating a fragmented service delivery system; and necessity has made them creative in stretching service dollars. These agencies, or other similarly qualified local organizations, should become the "one stop" central point of contact where non-frail seniors can get all the information they need rather than having to contact numerous agencies in order to obtain needed services. States, many of which have already developed workable programs, should retain considerable self-determination in the implementation of a long-term care system but with clear federal standards, guidelines and oversight.

Home Care

This nation's current long-term care policy has a strong institutional bias because the reimbursement system allows payment for institutional care, but not for home care. That trend is slowly changing as we see more Medicaid dollars going towards community-based care.

Seniors prefer care in their homes surrounded by familiar objects and sounds. As seniors lose the acuity of senses, familiarity of environment becomes increasingly important for retaining a sense of control and independence.

Unfortunately, home care is too expensive for many seniors to manage on limited income. One National Committee member from Daly City, California, felt she had nowhere to turn:

> I am 55 years old, and my husband is 77 and suffers from emphysema. I am paying $320 a week for a trained practical nurse to come to the house to take care of him. At this stage of his illness, all I can do is to make him comfortable. I run our small business by myself. I have used all my savings and have borrowed money and am looking to borrow more. After he dies, I will be destitute because I have to start paying back this money some of it at 20% interest. I am wrung out physically, emotionally, and financially. I have nowhere to turn.

Another member from Southbury, Connecticut, tells her story:

> In May, 1982, my husband had an accident, resulting in a spinal injury. He is mostly paralyzed, confined to a wheelchair. He is now 76 and I am 74. We are people of moderate means living on social security and pensions. At the time of the accident, medicare and other insurance helped us out financially. Now we receive no compensation for home care, which we must have, and physical therapy, which is necessary for my husband if he is not to deteriorate. Last year we spent $13,284.12 for health care. This is a big part of our budget. Please help us.

Examples such as these are countless. More reimbursement of home care through a unified payment system is clearly needed. To supplement the formal system of paid home care services, a pilot program of a more informal system of bartering has shown promise. Organized through a central office, individuals can receive credit hours for providing services to others -- they can buy and sell services. For example, a senior who is able to drive her car, can receive credit for taking someone for his or her medical appointment. In turn, she may use that credit toward something she is unable to do, for example, laundry. This system of bartering should be expanded.

Home delivered meals through the Older Americans Act should be expanded. It is a life saver for someone who is unable to prepare their own meals. Many of the seniors who have come to depend on their daily hot meal at a nutrition site, are now frail and no longer able to come to the senior center. Home delivered meals should be available to these people especially if they have no other alternative. "Meals on Wheels" is one of the vital programs that should never have to experience a waiting list. A meal is something that cannot wait.

Caregivers

Another issue with home care is the shortage of caregivers. We depend on family, friends and neighbors to provide between 80 and 90 percent of long-term care services. To encourage the continuation of this informal system, we should reimburse trained family caregivers for their efforts. Many caregivers find it necessary to quit their jobs in order to care for a spouse or parent. And yet they cannot manage without an income. Many states use the 2176 Medicaid waiver program to pay family members as home care aides. According to the Older Women's League, seventy percent of states have some arrangement for paid family caregiving, either through the waiver program, state tax credits or state supplements to SSI. Another way to help caregivers, is to amend the Social Security law to provide caregivers of disabled beneficiaries the same benefits they'd be eligible to receive if they had reached full retirement age. Paying family caregivers not only helps the family financially, it also acknowledges the value of caregivers' hard work. Care recipients frequently prefer family caregivers.

We need a national policy of family leave to further support our informal caregiving system. We need to protect the working caregivers of seniors – whether they are children or spouses of frail or seriously ill seniors – from losing their jobs when taking leave becomes necessary to provide temporary care. It is essential that caregivers are assured the continuation of their health insurance and other benefits during these absences.

An untapped pool of home care chore and shopping assistants is this nation's college students. Chore services can be arranged to fit the schedule of students. In addition to providing meaningful part-time work for cash-short students, it would help break down barriers between the old and the young in our society. Linkages between home care providers and colleges around the country should be encouraged through work study programs. Grants could be given to organizations willing to develop a model project. This approach is working in Scandinavian countries.

Institutional Care

Nursing homes will continue to be an important and necessary part of our long-term care system. However, we should consider limiting the development of new nursing home beds while providing more community services. This would help to alleviate the institutional bias we have experienced in this country up to this point. However, we should develop more settings for specialized problems such as victims of Alzheimer's disease. Needs in this area remain great. We should shift the emphasis from institutional care to home care by using the pre-admission screening requirement under recent nursing home reform law as a tool to redirect nursing home bound seniors to community-based setting.

While we consider a long-term care payment system of institutional care, we need to reexamine our current concept of nursing homes as extensions of hospitals. Nursing homes have nurses' stations, hospital beds, institutional furnishings, and multiple beds per room providing little privacy. Many residents are sedated with drugs or tied to their chairs or beds – ostensibly for their own safety. Before we get even more entrenched in a medical model perspective of nursing homes, we must recognize that our current course of restraining and controlling residents leads to a dehumanization of residents. When seniors move to a nursing home, whether for a few months or permanently, their rooms become their homes and with it comes the right to self-determination. The staff should not assume total responsibility for the resident's life, health and welfare. Rather it is the staff's responsibility to make all necessary treatment, care and oversight available to the resident in as pleasant and as home-like an atmosphere as possible.

This sense of control of one's life carries over into the method of payment. Control is best retained when the senior continues to pay, in-part, for the nursing home stay. This gives a sense of dignity and allows the resident to contribute what shelter and food would have cost were he or she still living in the community. Few want to lose the sense of control and self-worth by having the public pay for everything.

QUALITY

Quality assurance must be an integral part of any long-term care system. In order to provide quality care, we must have a sufficient pool of trained, caring, professional caregivers. The nation's diminishing pool of professional caregivers in nursing homes and home care settings must be addressed by improving the image of these vital jobs. Increased educational standards required under recent law will likely drive up wages, and gradually improve conditions for nurse aides.

To assure that only necessary services are received, the assessment and care coordination functions must be separated from service providers. While the care needs assessors are responsible for recommending only needed services, providers would benefit from providing as many services as possible. Care coordinators can serve in the same agency as assessors, but at the same time, they must serve as advocates for seniors – the person to whom the senior can turn for help when services are inadequate or of poor quality.

FINANCING OPTIONS

Expanding coverage to long-term home care and institutional care is clearly costly. The only way to finance long-term care is with broad-based financing. National Committee members have indicated that they want to pay their share for benefits that are useful to them. Our last survey showed that a clear majority, 61%, would be willing to pay the Medicare beneficiary surtax if benefits included long-term care.

Several ideas are worth looking into. For example, instead of Medicare paying a set amount for nursing home stays after a certain period, a percentage of the senior's income could be used toward the nursing home stay. Again an example can be taken from a Scandinavian country where residents pay for their nursing home stay with their Social Security check and 60% of other income – up to the full cost of the stay. A set monthly personal allowance is assured and the senior's assets are not touched. Estates are taxed at a time when seniors no longer need their assets.

If copayments and deductibles are set at fixed amounts, the near poor could be protected by requiring Medicaid to pay these out-of-pocket costs. To protect individuals with income above the poverty line, a sliding scale could also be used so that, for example, Medicaid would pay 100% of Medicare copayments and premiums up to 125% of the poverty line but only pay 50% of copayments and premiums up to 200% of the poverty line. This solution avoids means testing of Medicare benefits, while still protecting the poor and near poor.

The National Committee has long advocated eliminating the wage base on the Medicare payroll tax and making Medicare coverage mandatory. All workers pay 1.45 percent of their wages towards Medicare except the five percent of workers with earnings above $48,000 and state and local government employees who are not covered by Social Security. Eliminating the wage base would make the payroll tax less regressive and provide sufficient funding for a long-term home health care program similar to last year's proposal by the late Congressman Pepper.

Assessment and care coordination funding would not have to come out of Medicare and Medicaid, but could be funded through the Older Americans Act to keep this function more aligned with social services rather than the medical model.

In addition to public solutions, private solutions must be sought in terms of better, more affordable long-term care insurance products. To encourage employers to offer long-term care insurance to employees, the tax code should be amended to provide tax treatment of long-term care coverage similar to that afforded health insurance and life insurance. Another incentive for private insurance is to make it simple for employees to convert their life insurance to long-term care insurance at a time in the employee's life when most family obligations have been met. Once the children are through college, the insured has less need for life insurance and more need for long-term care insurance. A third option would be to allow for a tax free conversion of assets in an IRA in order to purchase private long-term care insurance.

The National Committee believes that a public-private solution to long-term care is necessary. Private solutions alone, however, can only provide modest help to those with long-term care needs and the absence of a public long-term insurance program remains a barrier to the full development of private long-term care supplemental insurance policies. Also, long-term care insurance products must meet minimum federal standards and be subject to federal oversight and sanctions.

CONCLUSION

While many essential parts of a long-term care system have not been developed in this statement, such as affordable housing, congregate housing, adult day care and transportation, they remain critical and should be included in a comprehensive long-term care plan. It is easy to agree on the need for all these services but harder to find the financial resources to pay for them. The National Committee pledges to work with other interested parties to provide health insurance coverage for all Americans including long-term care for people of all ages.

Representative GRADISON. Thank you very much, Mrs. McSteen. We will now hear from Ms. Jean McGuire.

STATEMENT OF JEAN McGUIRE, EXECUTIVE DIRECTOR, AIDS ACTION COUNCIL

Ms. MCGUIRE. Good morning. I am Jean McGuire, executive director of the AIDS Action Council, the national public policy arm of AIDS service organizations around the country. I am happy to be here today representing the interests of those who are working on the front lines of this epidemic.

People with AIDS and HIV infection have become the newest victims of this country's unwillingness to grapple with the health care coverage and delivery issues which continue to disenfranchise people daily.

As Senator Pepper knew, there is perhaps no arena in which that is more true than the arena of long-term care. Yet, in spite of incredible obstacles I am proud to say that the experience of our community-based AIDS service organizations over the last 8 years, truly affirm Senator Pepper's vision that compassion and cost effectiveness can both be served through systems of home-based and other nonacute care alternatives.

What these communities have been able to accomplish through ingenuity and considerable volunteer commitment over the first decade of this epidemic is about to collapse. Significantly increasing caseloads will demand more than ingenuity and require something beyond the resiliency and commitment of volunteers. It is time to move forward to assure that models providing for a continuum of long-term care services are developed, and that reimbursement mechanisms are put securely in place so that all of our Nation's at-risk citizens, and that is all of us, can expect to find a humane caregiving situation should we or our families face disabling illness or disease.

As we seek to focus today on solutions to the long-term care concerns, I would like to discuss some of the models of care which have been so important in the HIV epidemic and which I know have served other at-risk populations as well.

You are probably familiar with the so-called San Francisco model, which is the type of volunteer support, integrated HIV care system which has been replicated in many parts of this country already. Whether in San Francisco, Chicago, or Seattle, what has been intrinsic to the success that these models of care have experienced seems to be the following—a well-structured and identifiable case management system; close integration of primary, acute and home-based care supports; the willingness to support or fund nontraditional health-related services, meal preparation, chore assistance, transportation, adult care, among others; a commitment to provide emotional support through buddy and other mental health programs; a commitment to keeping people in their homes or in community-based systems of care as long as possible; close collaboration with those acute and skilled nursing centers which provide intermittent or end-stage care; collaboration with local and State health care planning and reimbursement agencies to assure flexibility and utilization of dedicated State and local appropriations, along with other public health reimbursement streams, and finally, a well-coordinated and adequately supported system of volunteer help.

As you can see to a great extent the salient elements of the HIV models of community-based care have very much mirrored the service recommendations which were contained in Senator Pepper's long-term care proposal last year, it recognized, as he did, both the need to shift from our institutional bias with this intense resource absorption and the need to rely heavily on integrated models of care with flexible utilization of reimbursement streams.

I'm sure that during the course of these hearings you will hear from many individuals who will recite what we already know to be the severe limitations inherent in benefit structures, institutional bias, and the inequities in coverage of our public and private health care reimbursement systems.

In addition, you will have repeated the very and political challenges so well exemplified in the current controversy over the catastrophic bill which will be faced when changing the coverage or funding structures of any of these systems. The reality is that without resolution of the limitations we know exist, we still don't avoid paying for the care people need.

We just pay for it through considerably more inefficient mechanisms—uncompensated care, lost employment of caregivers, et cetera, which almost always at a greater cost deliver what we know to be less humane and comprehensive care.

I don't have the answer in terms of fashioning incremental improvements to long-term care financing. What is clear is what must be emphasized—individual determination, comprehensive service integration, and flexibility in the reimbursement structures.

The assumptions that partially guide and only partially guide, unfortunately, community sharing of acute and primary costs, must be expanded to include long-term care so that we, as a Nation, see such care as a need that might arise for any of us. If well constructed, systems of long-term care can be cost efficient and can incorporate appropriate care and cost management strategies.

I have attached for information for the Commission the recommendations of the national organizations responding to AIDS which address a number of the primary and long-term care issues that are affiliated with HIV care. We look forward to collaborating with this Commission and with the many groups that you are hearing from today in truly framing an agenda that we can realize together and capitalizing on the momentum that the Senator gave us in the last years of his life.

Thank you.

[The prepared statement of Ms. McGuire follows:]

AIDS
Action
Council

Testimony On
LONG TERM CARE

submitted to

THE PEPPER COMMISSION

Thursday, October 5, 1989

submitted by
Jean McGuire
AIDS Action Council

Good morning. I am Jean McGuire, Executive Director of the AIDS Action Council, the national public policy arm of AIDS service organizations around the country. I am happy to be here today representing the interests of those who are working on the frontlines of this epidemic. In discussing the issues of AIDS and HIV within the context of long term care, the Council believes strongly that the ultimate answer to many of the health care issues raised by the AIDS epidemic lies in a mutual commitment with advocates for the elderly, the disabled and the poor to craft meaningful systemic change. This Commission may well be the start of such an exciting partnership.

Introduction

People with AIDS and HIV infection have become the newest victims of this country's unwillingness to grapple with the health care coverage and delivery issues which continue to disenfranchise people daily. As Senator Pepper knew, there is perhaps no arena in which that is more true than the arena of long term care. And yet, in spite of incredible obstacles, I am proud to say that the experience of our community-based, AIDS service organizations over the course of the last eight years truly affirms Senator Pepper's vision that compassion and cost effectiveness can both be served through systems of home-based and other non-acute-care alternatives.

But what these communities have been able to accomplish through ingenuity and considerable volunteer commitment over the first decade of this epidemic is about to collapse. Significantly increasing caseloads will demand more than ingenuity and require something beyond the resiliency and commitment of volunteers. It is time to move forward to assure that models providing for a continuum of long term care service are developed and that reimbursement mechanisms are put securely in place so that all of our nation's at-risk citizens - that is, all of us - can expect to find a humane caregiving situation should we or our families face disabling disease or illness.

It is also important to realize that establishing these systems of care will do more than enhance the lives of those whom we aim to serve. Soundly constructed, a continuum of long term care supports will help people with long term disabling conditions to realize greater independence and to perhaps become more productive within the workforce. It has long been the stand of the World Institute on Disability and so many others that the greatest obstacle to full employment faced by many persons with disabilities is their lack of access to disability-related health care supports, including elements of long term care. It is very likely that as we see HIV disease change from a quickly fatal illness to something resembling a chronic condition, there will be increasing needs for long term care supports to enhance independent living and lesser needs for care devoted to easing dying. In fact, that transition is already taking place in terms of the design of services and those who are increasingly in need.

Models of Care

As we seek to focus on solutions to the long term care concerns, I would like first of all to discuss some of the models of care which have been so important in HIV, and which I know have served other at-risk populations well. You are probably familiar with the so-called "San Francisco model" which is the type of volunteer-supported integrated HIV care system which has been replicated in many parts of the country.

Whether in San Francisco, Chicago, or Seattle, what has been intrinsic to the success these models of care have experienced seems to be the following:

- a well-structured and identifiable case management system;
- close integration of primary, acute and home-based care supports. This integration has included the development of a surprising level of understanding of drug development and experimental drug access issues so that providers at diverse levels of care have been more informed than is frequently the case about available treatment regimens and drug interactions;
- the willingness to support (or fund) non-traditional health related services: meal preparation, chore assistance, trans-

portation, and adult day care, among others;

- a commitment to providing emotional support through buddy systems and other mental health programs;
- a commitment to keeping people in their homes or in community based systems of care as long as possible;
- close collaboration with those acute and skilled nursing settings which provide intermittent or end-stage care;
- collaboration with local and state health care planning and reimbursement agencies to assure flexibility in utilization of dedicated state and local appropriations along with other public health reimbursement streams;
- and finally, a well coordinated and adequately supported system of volunteer help.

The success of even the early stages of this model prompted the establishment through the Health Resources and Services Administration of the adult and pediatric health services demonstration projects now in place at almost 20 sites throughout the country. The evolution of integrated models of care in high prevalence areas has also prompted allocation of considerable private foundation dollars from both Robert Wood Johnson and the Ford Foundation. And, over the last two federal funding cycles we have seen the allocation of additional, if somewhat limited, HRSA resources to prompt integrated planning efforts in jurisdictions with lower incidence rates.

As you can see, to a great extent the salient elements of the

HIV models of community based care have very much mirrored the service recommendations contained in Senator Pepper's long term care proposal. They recognize, as he did, both the need to shift from our institutional bias with its intense resource absorption, and the need to rely heavily on integrated models of care with flexible utilization of reimbursement streams.

A heartwarming but particularly vulnerable aspect of the HIV model is the incredible reliance on volunteer support. We are well aware of how this is beginning to break down in the context of HIV as the epidemic continues on and the numbers increase so drastically. Certainly, the volunteer support has created an energy that we want to harness and continue to expand. But it would be foolish to develop a national strategy around long term care that relied so heavily on volunteer availability.

However, an important element to take forward from this experiment is the recognition that reimbursement systems must be modified to include strategies to support paraprofessionals in the course of meeting disability-related long term care needs.

Reimbursement

I am sure that during the course of these hearings you will hear from many individuals who will recite what we already know to be the severe limitations inherent in benefit structures, the institutional bias, and the inequities in coverage of our public and private health care reimbursement systems. The lack of uniformity in our state Medicaid programs, the ongoing difficulties with the disability determination process under Social Security, the 29 month waiting period for Medicare eligibility and the exclusionary activities of private insurers are only a few of the often repeated tragedies within our financing systems.

In addition, you will have repeated the varying political challenges -- so well exemplified in the current controversy over the catastrophic bill -- which will be faced when changing the coverage or funding structures for any of these systems. The reality is that without resolution of the limitations we know exist, we still don't avoid paying for the care people need. We just pay for it through considerably more inefficient mechanisms (uncompensated care, harmfully late care-seeking,etc.), which -- almost always at a greater cost -- deliver what we know to be less humane and comprehensive care.

I don't have the answer in terms of fashioning incremental improvements to long term care financing. What is clear is what must be emphasized: individual determination, comprehensive service integration, and flexibility in reimbursement. The assumptions that partially guide community sharing of acute and primary care costs must be expanded to include long term care so that we as a nation see such care as a need that might arise for any of us. If well-constructed, systems of long term care can be cost efficient and can incorporate appropriate care and cost management strategies.

I have attached for your review the legislative goals of the National Organizations Responding to AIDS (NORA). NORA is a coalition, chaired by AIDS Action Council, of over 140 national agencies working on behalf of those who are affected by the HIV epidemic. There are a number of primary and long term health care improvements which have been the focus of some of our legislative discussions.

To these recommendations I would add an additional concern. It is very clear that the types of systemic changes we all seek are not going to happen in the short term. My hope is that your Commission can give our collective efforts a momentum that they continue to lack. However, I also believe that, in the context of HIV, we are seeing the impact of a particular disease truly eviscerate the poverty health structures in a number of our communities. While I believe that the best health care financing improvements we make are those that are system-wide, I also believe that the impact of this disease may require some disease-specific remedies if we are to alleviate the impact on the rest of the poverty health system. At a minimum, we may be needing to address the ability to qualify individuals for coverage for those early intervention efforts we know can keep them healthier longer and in less need of primary, acute and long term care support.

I also think it is important to revisit the notion of buying into Medicaid as an avenue for providing coverage for people who are medically uninsurable since I do not believe that the current trend of risk pool development is satisfactorily meeting their needs.

The AIDS Action Council looks forward to continuing to work with you to define a long term care agenda for the future that can be embraced by all Americans, including those who are fortunate enough to be temporarily able-bodied and well.

National
Organizations
Responding to
AIDS

LEGISLATIVE ISSUES AND GOALS FOR THE 101st CONGRESS

APRIL, 1989

a coalition convened by
AIDS ACTION COUNCIL
2033 M Street, N.W. • Suite 801 • Washington, D.C. 20036
(202) 293-2886 • FAX (202) 296-1292

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LEADERSHIP

JEAN McGUIRE
Chair, NORA
Co-Chair, Appropriations Task Force
AIDS Action Council
Executive Director
(202) 293-2886

WILLIAM BAILEY
Co-Chair, Prevention Task Force
American Psychological Association
AIDS Policy Officer
(202) 955-7653

SUSAN CAMPBELL
Chair, Pediatric AIDS Task Force
American Academy of Pediatrics
Assistant Director, Department of
Government Liason
(202) 662-7460

CURTIS DECKER
Co-Chair, Civil Rights Task Force
National Association of Protection
and Advocacy Systems
Executive Director
(202) 546-8202

CHAI FELDBLUM
Co-Chair, Civil Rights Task Force
American Civil Liberites Union
Legislative Counsel
(202) 544-1681

CARLTON LEE
Co-Chair, Research Task Force
Human Rights Campaign Fund
Legislative Counsel
(202) 628-4160

JEFF LEVI
Co-Chair, Appropriations Task Force
National Gay and Lesbian Task Force
Executive Director
(202) 332-6483

KATHERINE McCARTER
Co-Chair, Prevention Task Force
American Public Health Associaton
Associate Executive Director
(202) 789-5651

DONNA RICHARDSON
Co-Chair, Care Task Force
American Nurses' Association
Director of Congressional
and Agency Relations
(202) 789-1800

TOM SHERIDAN
Co-Chair, Care Task Force
AIDS Action Council
Director of Public Policy
(202) 293-2886

STEVE SMITH
Co-Chair, Research Task Force
Human Rights Campaign Fund
Legislative Counsel
(202) 628-4160

WENDY WERTHEIMER
Co-Chair, Appropriations Task Force
American Social Health Association
Deputy Executive Director
(202) 543-9129

PAT WRIGHT
Co-Chair, Civil Rights Task Force
Disability Rights Education and
Defense Fund, Inc.
Executive Director
(202) 328-5185

National
Organizations
Responding to
AIDS

APPROPRIATIONS TASK FORCE

Jeff Levi, Co-Chair
NORA Appropriations Task Force
National Gay and Lesbian Task Force
(202) 332-6483

Jean McGuire, Co-Chair
NORA Appropriations Task Force
AIDS Action Council
(202) 293-2886

Wendy Wertheimer, Co-Chair
NORA Appropriations Task Force
American Social Health Association
(202) 543-9129

I Total Recommended AIDS Spending

- Appropriate $2.152 billion for FY 1990 for AIDS spending by the Department of Health and Human Services.

- This request is approximately $452 million greater than the President's request for 1990. This reflects the needs for AIDS activities as determined by the agencies, and is in line with the continuing recommendations of the Institute of Medicine for $2 billion in spending on research and prevention by 1990. Nonetheless, even this higher level provides insufficient resources for a number of priority programs authorized by Congress last year in P.L. 100-607.

II Priorities For Funding

- Our highest priorities for expansion of federal efforts in the fight against AIDS in 1990 are increased support for care for persons affected by HIV, ranging from direct primary care for low income individuals to mental health services for those infected with HIV, and wider efforts to prevent the spread of HIV infection through community-based, targeted activities (ranging from expanded access to drug abuse treatment to behavior change counseling and education to prevent sexual transmission of HIV). Our progress in research is meaningless unless we assure access to those treatments for all Americans, not just those wealthy enough to afford them. Our hope for reducing care costs in the long-term are directly related to our willingness to invest in prevention programs - the only vaccine against HIV we will have for some time.

- We continue to be concerned about the level of research activity into treatments and a cure for HIV-related diseased. As the number of potential therapies increases, we must be certain that the NIH has sufficient resources to expand its capacity to test those drugs. Funds, staffing, and space should no longer be the excuse for delays in getting promising therapies into the clinical trial system. We are particularly excited by the potential of the NIAID's new community-based clinical trial efforts, as authorized in P.L. 100-607, and believe it merits a higher level of funding than anticipated by the President's budget and the NIH request.

Summary of NORA AIDS Recommendation for FY 1990 (in millions)

PHS AIDS Programs	2,046
Other	35
TOTAL LABOR/HHS REQUEST	2,081
[Total AIDS recommendation with FDA ($71 m)	2,152]

PHS-wide concerns and priorities

Agency	FY 89 (in millions)	FY90 (Pres.)	FY90 (NORA)
ADAMHA	175	218	289
CDC	382	474	584
HRSA	45	56	254
Indian HS		1	1
NIH	607	753	900
OASH	13	41	18
Total PHS AIDS Programs Labor/HHS	1,222	1,543	2,046

CARE TASK FORCE

Donna Richardson, Co-Chair
NORA Care Task Force
American Nurses' Association
(202) 789-1800

Tom Sheridan, Co-Chair
NORA Care Task Force
AIDS Action Council
(202) 293-2886

I Medicaid

- Support the improvement of eligibility standards and increase options for people above state determination levels, including options to buy into Medicaid services
- Support increased utilization of 2176 waivers and initiatives to include home and community care as part of optional services covered
- Support the utilization and reimbursement of case management services designed to increase access to appropriate care
- Increase Medicaid reimbursement rates to more accurately reflect the cost of care for people with long term and catastrophic illnesses and decrease the level of uncompensated care

II Medicare

- Support the lowering of disability determination criteria from 24 months to 18 months
- Reform the interpretation and implementation of Social Security disability determination

III Private Insurance

- Oppose the pre-existing condition clauses currently utilized by insurance companies

CARE TASK FORCE

- Examine the impact of current COBRA extensions and support of incremental improvements
- Support limitations on the use of HIV testing
- Support initiatives that provide coverage to the uninsured and underinsured
- Support benefit structures that adequately cover people with HIV infection and their care needs

IV Health\Human Services

- Support services aimed at early intervention and asymptomatic care
- Support increased programs and funding options for mental health and counseling programs
- Support specialized foster care and family support programs
- Increase federally financed support for home care, hospice and other community care models
- Support initiatives aimed at assisting states and localities in developing a comprehensive continuum of services for people with HIV infection
- Support programs and services targeting poverty populations to ensure access to primary health care
- Support the development of a federal/state matching program to supplement the purchase of drugs which are too costly for consumers with life threatening illnesses to purchase

V Caregiver Resources

- Support initiatives to increase the recruitment and retention of primary health care providers, including equitable reimbursement
- Increase remuneration for professionals and paraprofessionals providing alternative care, e.g. day, respite, home and hospice care
- Increase funding for health and human service professional education training

National
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CIVIL RIGHTS TASK FORCE

Curt Decker, Co-Chair
NORA Civil Rights Task Force
National Association of Protection
and Advocacy Systems
(202) 546-8202

Chai Feldblum, Co-Chair
NORA Civil Rights Task Force
American Civil Liberties Union
(202) 544-1681

Pat Wright, Co-Chair
NORA Civil Rights Task Force
Disability Rights Education
and Defense Fund, Inc.
(202) 328-5185

I Anti-Discrimination Protection

- Support a comprehensive federal bill that prohibits discrimination on the basis of disability, including all stages of HIV disease (from HIV infection to AIDS), in the following areas:

  Employment: Private employers should not be allowed to discriminate against a person with HIV disease who is otherwise qualified for the position

  Public Accommodations: People with HIV disease should not be turned away from places ordinarily open to the public

  Public Service: People with HIV disease should have equal access to all public services

- Oppose any efforts to exclude people with HIV disease from coverage or to limit coverage under such a broad-based disability bill

II Confidentiality and Informed Consent

- Support enactment of informed consent requirements for all HIV antibody testing, and confidentiality protections for HIV related medical information

CIVIL RIGHTS TASK FORCE

- Oppose mandatory HIV testing or reporting requirements on the state and federal level
- Support voluntary partner notification systems that are consistent with public health guidelines

III Legal Advocacy

- Support expansion of legal resources to provide legal and advocacy services to those affected by HIV disease

National
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AIDS

PEDIATRIC AIDS TASK FORCE *

Susan Campbell, Chair
NORA Pediatric AIDS Task
Force
American Academy of
of Pediatrics
(202) 662-7460

I Federal Pediatric AIDS Policy

- Direct the Secretary to prepare an annual report on total federal spending for pediatric HIV infection
- Direct the Secretary to facilitate communication and cooperation among the HHS agencies involved with pediatric HIV infection
- Give funding priority to programs emphasizing family-centered, community-based, coordinated systems of care
- Ensure that expanded funding for pediatric AIDS does not come at the expense of existing health, mental health and social service programs for family and children
- Provide civil rights protections for children infected with HIV and their caregivers

II Social Services

- Approve $5 million in supplemental appropriations for FY 1989 to fund the Abandoned Infants Assistance Act
- Appropriate the full authorization of $20 million for the Abandoned Infants Act for FY 1990
- Increase the availability of shelters and services for adolescents through additional funds for the Runaway Homeless Youth Act and full funding of $5 million for the Transitional Living Grant Program

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* The Pediatric AIDS Task Force addresses HIV related issues affecting persons up to the age of 21 years.

PEDIATRIC AIDS TASK FORCE

III Health Care

- Provide Medicaid coverage for all poor children as well as near poor women and infants
- Expand Medicaid coverage for the full range of health care and social services needed by HIV-infected children, including home and community-based services as alternatives (when appropriate) to inpatient hospital care
- Enhance Medicaid reimbursement adjustments for care providers serving a disproportionate share of low income and Medicaid patients
- Appropriate $24 million grants for pediatric AIDS health care demonstration project grants for FY 1990
- Appropriate additional funds for Community and Migrant Health Center grants for FY 1990
- Appropriate $10 million for grants for targeted outreach, confidential testing and counseling, and family planning services to women and adolescents who are at risk for HIV infection or who are already infected

IV Education

- Provide age-appropriate HIV education to all students, starting in kindergarten and continuing through grade twelve
- Enact the AIDS Youth Education Act, which recognizes the special informational and counseling needs of all youth, particularly those at high risk
- Coordinate outreach, education, counseling and prevention efforts for minority youth
- Direct the Secretary of Health and Human Services and the Secretary of Education to co-chair a task force on comprehensive school based health programs, in an effort to develop comprehensive health education programs at the local level

V Research

- Bolster existing NIH biomedical research activities and expand the number of NIH supported clinical trials for pediatrics
- Increase funding to meet the necessary and substantial costs associated with the multidisciplinary approach that combines patient care, treatment, research and the provision of family services
- Provide NIH with additional administrative support in the form of FTE's
- Direct the Food and Drug Administration to review their guidelines regarding testing of agents in infants, children and adolescents in light of the rapid disease progression and devastating mortality rates among infected children

National
Organizations
Responding to
AIDS

PREVENTION TASK FORCE

Bill Bailey, Co-Chair
NORA Prevention Task Force
American Psychological
Association
(202) 955-7653

Katherine McCarter, Co-Chair
NORA Prevention Task Force
American Public Health
Association
(202) 789-5651

I Education

- Expand, improve, and evaluate AIDS education and prevention programs, especially for hard to reach populations, with a focus on the efforts of community-based service providers
- Defeat restrictions on AIDS education efforts
- Monitor CDC regulation of state and local AIDS community based education efforts
- Encourage the development of AIDS education programs which involve adolescent peer education
- Increase HIV education aimed at women, adolescents, minorities, gay and bisexual men, and special populations (e.g. homeless, developmentally disabled, mentally ill, institutionalized populations)
- Extend "targeted" education to school boards, employers, health care professionals, youth service workers, and teachers
- Monitor efforts of new office on Comprehensive School Health Education
- Promote TV public service messages on HIV transmission and prevention
- Promote education intended to reduce stigmatization of persons with HIV infection and persons in high risk groups

a coalition convened by
AIDS ACTION COUNCIL
2033 M Street, N.W. • Suite 801 • Washington, D.C. 20036
(202) 293-2886 • FAX (202) 296-1292

PREVENTION TASK FORCE

- Ensure that federal programs incorporate information on HIV prevention, human sexuality, substance abuse, and teacher/leader training and evaluation

II Services

- Expand and improve confidential HIV counseling and testing programs
- Monitor the status of Title X program and regulations with a focus on their impact on HIV infected women
- Encourage local public health officials to make condoms readily available to sexually active persons
- Enable local public health authorities to make treatment available on demand for sexually transmitted diseases
- Ensure funding and political support for policy of drug abuse treatment upon demand

III Research

- Increase behavioral and social science research and evaluation, including randomized field trials of community-based prevention programs
- Ensure the implementation of the NICHD Survey of Human Sexual Behavior
- Establish research on needle exchange/free needles
- Reformulate CDC "family of surveys" as probability samples
- Extend newborn infant seroprevalence survey to all U.S. newborns
- Encourage the Assistant Secretary for Health to take lead responsibility for developing an evaluation strategy on the effectiveness of AIDS interventions

RESEARCH TASK FORCE

Carlton Lee, Co-Chair
NORA Research Task Force
Human Rights Campaign Fund
(202) 628-4160

Steve Smith, Co-Chair
NORA Research Task Force
Human Rights Campaign Fund
(202) 628-4160

I Research

- **Increase Public Health Service FTEs for AIDS activities per the Omnibus Health Programs Extension Act (P.L. 100-607)**
- **Increase financial incentives to attract and retain health and scientific professional and technical personnel in federal agencies**
- **Expand and upgrade facilities for federal agencies involved in research and drug review**
- **Support necessary research uses of animals, fetal tissue, and recombinant DNA, within appropriate safety and ethical guidelines**
- **Increase resources for training of scientists**
- **Support expansion of behavioral research**
- **Support scientific surveys of sexual behavior**
- **Support confidentiality of research data that would identify participants**

II Access to Treatment

- **Assess the ability of current regulatory practices to make investigational treatments available to HIV-infected persons**

RESEARCH TASK FORCE

- Assess the impact of marketing approval standards on the availability of treatments for life-threatening conditions
- Expand access to clinical trials for women, children, hemophiliacs, intravenous drug users, and minorities
- Increase resources for community-based research
- Include primary care providers and consumers in the design of research and treatment protocols
- Assess appropriate role of federal government in licensing and pricing of treatments developed or tested with government funds
- Create mechanisms to transfer research results to primary care providers
- Assess proposals to allow participants in trial and treatment protocols to waive civil remedies for adverse effects of investigational treatments
- Assess emerging trends in liability for adverse effects of vaccines in trials and marketing

National Organizations Responding to AIDS

Revised April 6, 1989

ORGANIZATION

AIDS Action Council
AIDS Education Bureau
AIDS National Interfaith Network
Alan Guttmacher Institute
American Academy of Family Physicians
American Academy of Pediatrics
American Anthropological Association's Task Force on AIDS
American Association for Counseling and Development
American Association for Marriage and Family Therapy
American Association of Occupational Health Nurses
American Association of Univeristy Affiliated Programs
American Association of University Affiliated Programs
American Bar Association
American Civil Liberties Union
American College Health Association
American College of Physicians
American Federation Labor & Congress Industrial Organizations
American Federation of State County and Municipal Employees
American Federation of State, County and Municipal Employees
American Federation of Teachers
American Foundation for AIDS Research
American Home Economics Association
American Hospital Association
American Jewish Committee
American Jewish Congress
American Lung Association
American Medical Association
American Medical Records Association
American Nurses' Association
American Psychiatric Association
American Psychological Association
American Public Health Association
American Red Cross
American Social Health Association
American Society of Internal Medicine
Americans for Democratic Action
Association for Retarded Citizens
Association of Maternal and Child Health Programs
Association of People for the American Way
Association of Schools of Public Health

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National Organizations Responding to AIDS

Revised April 6, 1989

ORGANIZATION

Association of State and Territorial Health Officials
Catholic Health Association of the United States
Center for Population Options
Child Welfare League of America
Chronic Fatigue Syndrome Information Institute Inc.
City of New York
City of Philadelphia
Committee for Children
Consortium of Social Science Associations
Consumer Health Strategies
Council of Jewish Federations
Disability Rights Education and Defense Fund Inc.
Environmental Mediation International
Equality Center
Hospice Association of America
Human Rights Campaign Fund
Industrial Biotechnology Association
Legal Action Center
National AIDS Network
National Alliance for the Mentally Ill
National Association for Home Care
National Association of Childrens Hospitals & Related Institutions
National Association of Community Health Centers Inc.
National Association of Counties
National Association of County Health Officials
National Association of Medical Equipment Suppliers
National Association of People with AIDS
National Association of Protection and Advocacy Systems
National Association of Public Hospitals
National Association of Social Workers
National Association of State Alcohol and Drug Abuse Directors
National Association of State Boards of Education
National Black Child Development Institute Inc.
National Community Research Initiative
National Conference of State Legislatures
National Council on Alcoholism
National Council on La Raza
National Education Association
National Family Planning and Reproductive Health Association
National Foundation for Infectious Diseases

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National
Organizations
Responding to
AIDS

Revised April 6, 1989

ORGANIZATION

National Foundation for Infectious Diseases
National Gay and Lesbian Task Force
National Health Care Campaign
National Health Law Program Inc.
National Hemophilia Foundation
National Hospice Organization
National Leadership Coalition on AIDS
National Lesbian and Gay Health Care Foundation
National Mental Health Association
National Minority AIDS Council
National Network of Runaway and Youth Services
National P.T.A.
National Puerto Rican Coalition
National Urban Coalition
National Urban League
Parents\Friends of Lesbians and Gays
Pettus-Crowe Foundation
Planned Parenthood Federation of America
Prospect Associates
Rainbow Lobby
Service Employees International Union
Synagogue Council of America
Task Force on AIDS and the Family
Union of American Hebrew Congregations
United Church Board for Homeland Ministries
United Food and Commercial Workers International Union
United States Conference of Local Health Officers
United States Conference of Mayors
Woman's National Democratic Club

Representative GRADISON. Thank you, Ms. McGuire. Ms. Zollar?

STATEMENT OF CAROLYN ZOLLAR, GENERAL COUNSEL AND DIRECTOR OF GOVERNMENT RELATIONS, NATIONAL ASSOCIATION OF REHABILITATION FACILITIES [NARF], ON BEHALF OF NATIONAL REHABILITATION COALITION [NRC]

Ms. ZOLLAR. Good morning. Mr. Chairman and members of the Commission, my name is Carolyn Zollar and I'm general counsel and director of Government relations for the National Association of Rehabilitation Facilities. This morning I am representing the National Rehabilitation Coalition comprised of national organizations of providers and consumers of rehabilitation services.

The people the coalitions represent have close personal experience with the issues of long-term care. I'd like to summarize our statement and briefly explain the nature of rehabilitation, generally, and in the context of long-term care. Rehabilitation is an essential component of the health care delivery system. Its goal is to restore an individual's maximum level of function and/or compensate for any residual disabilities.

An individual may require rehabilitation services due to accident, illness, or congenital anomalies—stroke is one of the predominant reasons for needing rehabilitation services among the elderly. Rehabilitation services include, but are not limited to, physician services, rehabilitation nursing, occupational therapy, physical therapy, speech language pathology, audiology, and vocational training delivered by an interdisciplinary team.

The problem of long-term care has been outlined extensively to this Commission. For rehabilitation, many of these problems are compounded. Many of us are not aware of the need for rehabilitation until we need it. When it is needed, you really need it, and finding it can be tricky.

An NARF and AHA [American Hospital Association] market study with the SRI Gallup Corp. showed little consumer, payer, physician, or union awareness of rehabilitation or the need for it except in life-threatening situations. They are unaware how it can help improve the general quality of life. Several studies have also shown the cost benefit of rehabilitation and I will refer and give this to the record, our monograph on Cost Benefits of Stroke Rehabilitation. Several independent insurance studies have shown the same.

The rehabilitation system, both at the acute care and long-term levels, is a patchwork quilt of services from Medicare, Medicaid, worker's compensation, and private insurance with its previously echoed strong bias for institutional care only. The system, therefore, does not adequately provide the restorative, and more meaningful in the long-term care context, maintenance needs for living as independently as possible.

If you have found a program the question of eligibility comes next. Very often age, income, employment, and/or disability are the determining factors without regard to functional ability. We submit that the individual's ability to function should be the determining factor for eligibility not solely age or income.

The third problem is the services covered. As I mentioned, the existing system is a patchwork quilt. Unfortunately, it does not carry the beauty of many of those quilts. In the long-term care area, to the extent the programs exist at all, it is spotty, not just patchwork and does not address, as I mentioned before, maintenance needs.

The risk for continued deterioration of a patient needed continuing care is continual and they will frequently be reinstitutionalized at great cost to them and to the system. Payment follows coverage criteria with rates of payments and levels of a denial always being contentious.

I'd like to summarize several of the coalition's recommendations and refer you to our testimony for the others. The NRC supports services that can be delivered at home or through community-based organizations such as rehabilitation facilities or by practitioners of rehabilitation services, thereby allowing people to live in as independent a setting as possible with a focus on a life of dignity at the highest quality providing autonomy and personal responsibility.

Public and private programs should provide coverage for persons with disabilities and not exclude them due to preexisting conditions or require unreasonable waiting periods. To this end, we recommend that the 2-year waiting period for Medicare benefits under SSDI [Social Security Disability Income] be eliminated.

The NRC recommends that eligibility for any program not be triggered by age and/or resources, income, but by ability to perform activities of daily living including mobility and communication. Several bills in Congress are examining this approach.

With respect to financing, to echo Mr. Gradison, this is the crux of the problem. If we had an answer, we wouldn't be here. Inadequate funding will simply support a haphazard and ineffective service delivery program. We have been supporting a combined public and private sector approach. Various options to explore include promoting long-term care insurance policies which follow appropriate standards and appropriate coverage; examining the question of reasonable cost-sharing, copay and sliding scale fees; reexamining national budget priorities; providing a checkoff on the income tax to establish a public fund for long-term care; and from NARF's perspective alone, examining the question of excise or user fees.

Motor vehicle accidents are highly correlated with injuries such as spinal cord and head injuries known to result frequently in long-term care needs. With respect to a benefit structure, we believe incrementalism is the appropriate path with a goal toward a comprehensive spectrum of medical rehabilitation and social services, both institutional, home and community-based.

I thank you for this opportunity and refer you to the balance of our statement.

[The prepared statement of Ms. Zollar and monograph referred to follows:]

NRC National Rehabilitation Caucus

A national [illegible] for the advancement of rehabilitation
through advocacy, education, research and communications

STATEMENT OF THE
NATIONAL REHABILITATION CAUCUS

American Hospital Association,
Section for Rehabilitation Hospitals and Programs

American Occupational Therapy Association

American Physical Therapy Association

American Speech, Language and Hearing Association

National Association for Home Health Care

National Association of Rehabilitation Facilities

National Easter Seal Society

American Association for Respiratory Care

American Academy of Physical Medicine and Rehabilitation

American Congress of Physical Medicine and Rehabilitation

BEFORE THE
UNITED STATES BIPARTISAN COMMISION
ON COMPREHENSIVE HEALTH CARE

OCTOBER 5, 1989

NRC National Rehabilitation Caucus

A national focus for the advancement of rehabilitation ... through advocacy, education, research and communication

EXECUTIVE SUMMARY

The National Rehabilitation Caucus (NRC) is comprised of national organizations representing consumers and providers of rehabilitation services as well as rehabilitation professionals.

An interdisciplinary team approach and case management are the key components of an integrated rehabilitation program. This system is hampered, however, by a patch-work quilt of services covered by Medicare, Medicaid, workers compensation and private insurance, if at all. Thus, the NRC submits the following recommendations to the Commission in an effort to improve access and coverage of rehabilitation services for persons with disabilities.

RECOMMENDATIONS

The NRC supports services that can be delivered at home or through community-based organizations, such as rehabilitation facilities, or by practitioners of rehabilitation services, thereby allowing people to live in as independent a setting as possible. This is simply the more preferable alternative for most individuals. To this end, the NRC has the following comments for the Commission to consider in fashioning its report pertaining to needs of the elderly and people with disabilities.

A . COVERAGE

Public and private programs should provide coverage for persons with disabilities and not exclude them due to preexisting conditions, or require unreasonable waiting periods. According to the World Institute on Disability, as many as one third of the SSDI beneficiaries have no health care during the two-year waiting period. This lack of coverage also includes lack of any Medicaid coverage. This is a crucial time period for a person with a disability as this is when the most benefit from rehabilitation services is usually realized. The NRC recommends that the two-year waiting period be eliminated.

Any final recommendations should assure coverage of the needs for all populations including the non-disabled elderly, as well as the potential long-term care needs of the poor, working poor, unemployed and employed.

B. ELIGIBILITY

The NRC recommends to the Commission that eligibility for any program not be triggered by age and/or resources (income and other) but by ability to perform activities of daily living, mobility and communication. Several bills in Congress currently take this approach.

C. OBJECTIVES

The objective of any program should be to allow the elderly or non-elderly people with disabilities to continue to live a life of dignity and of the highest quality with an emphasis on independence, autonomy and responsibility.

D. FAMILY SUPPORT

Support from the family and other informal systems should be encouraged. However, the health of an overburdened family member should not be jeopardized due to not having home health services for the disabled family member or the benefit of respite care.

E. BENEFITS

Benefits should cover a comprehensive, defined spectrum of appropriate medical rehabilitation, and social services, both institutional and home- or community-based, without financial bias in any direction. The traditional medical model does not serve all the needs of the disabled. Effective long term care also requires social services in order to be truly beneficial. Any final recommendations should recognize and cover the complete spectrum of the patient's rehabilitation needs. People who do not receive such services quickly deteriorate and often end up being readmitted to a hospital or a nursing home thus incurring additional costs to the system.

This continuum of coverage should be in addition to, rather than in replacement of, existing benefits and not used as a trade-off for, or limitation on, other benefits.

A comprehensive system should include the following services which are not included in current programs or policies: assisted devices and related services, respite, adult day care, homemaker-health aide, and psychosocial rehabilitation services.

F. CONTINUITY OF CARE

Continuity of care and coordination of appropriate services must be ensured. For example, case management is an indigenous part of the traditional medical rehabilitation model and should be included in the Commission's final recommendations. Such case management must be conducted by people with training in rehabilitation services.

G. EVALUATION

Each person seeking care should have an initial, multidisciplinary evaluation of medical and functional status which is periodically reviewed. That is, the patient's ability to perform all tasks of daily living should be established at the time of application for benefits to help in determining eligibility, as well as type, amount, duration, and frequency of therapy and placement.

H. FINANCING

Inadequate funding will simply support a haphazard and ineffectual service delivery system. A combined public and private sector approach is the most reasoned one. This is contemplated in part in the previously mentioned Brookings study. It does have the drawback, however, of being economically determined, usually by income and/or employment status.

We propose the following options for financing long term care programs and services:

- promoting long term care insurance policies which have appropriate standards
- requiring reasonable cost-sharing, co-pay and/or sliding scale fees
- re-examination of the national budget priorities
- providing a check-off on the income tax form to establish a public fund for long term care (i.e. $1.00 or other amount)

For further information you may contact Carolyn Zollar, General Counsel, Director of Government Affairs, National Association of Rehabilitation Facilities at (703) 648-9300.

NRC National Rehabilitation Caucus

A national voice for the advancement of rehabilitation [illegible]
through advocacy, education, research and communications

STATEMENT OF THE NATIONAL REHABILITATION CAUCUS

American Hospital Association,
Section for Rehabilitation Hospitals and Programs

American Occupational Therapy Association

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National Association for Home Health Care

National Association of Rehabilitation Facilities

National Easter Seal Society

American Association for Respiratory Care

American Academy of Physical Medicine and Rehabilitation

American Congress of Physical Medicine and Rehabilitation

BEFORE THE UNITED STATES BIPARTISAN COMMISION ON COMPREHENSIVE HEALTH CARE

OCTOBER 5, 1989

Dear Mr. Chairman:

This statement is submitted to the Commission by the undersigned participants of the National Rehabilitation Caucus (NRC). The NRC is a coalition comprised of national organizations representing providers of services, rehabilitation professionals and consumers of rehabilitation services. This statement addresses the responsibility of the Commission to review and make recommendations concerning the availability of comprehensive services, including long term care, for the elderly and disabled.

Our current system of care for these populations is a patch-work quilt and a function of luck, economics and geography. Most people use rehabilitation because of physical injuries or illness at various times throughout their lives--not just once. However, there is no comprehensive health package or system to deliver rehabilitation services.

Quality health care includes a broad spectrum of hospital, home and community-based rehabilitation services. Rehabilitation is tailored to the unique needs of the patient. Consequently, access to a variety of services in a range of settings maximizes an individual's opportunities to receive timely and appropriate care and maximizes individual functioning, independence, and ideally, return to a productive life.

I. THE PROBLEM

There is ample testimony on the future demographics of this nation. People are simply living longer. Twenty percent of the population will be over 85 years old by the year 2010. As noted in the report, Caring for the Disabled Elderly, Who Will Pay?, (Brookings Institution, 1988, Washington, D.C.) most older people remain physically active and capable of caring for themselves. Only one-quarter of Americans over age 65 in 1985 (6.3 million) had a disability. The prevalence of disability increases considerably with age.

Another group in need of long-term care services are children and working-age adults with disabilities who comprise a large percentage of this nation's 36 million persons with disabilities. As medical technology has increased the ability to save lives, the issue then becomes the quality of life and with what dignity these people will be able to live it. For the young who incur disabilities and who then become old, as well as older people with disabilities, the need for long-term care occurs long before age 65, 75, or 85.

A. COVERAGE

Existing health coverage does not adequately address the needs of many people. The problems in Medicare, Medicaid and commercial health insurance are magnified 100 fold when focused on a patient needing rehabilitation services. There are glaring gaps in coverage and payment for patients needing rehabilitation services and disabled individuals with residual impairments who incur continuing costs for medical, health and personal care needs. Worse yet, there are millions of citizens without any health insurance and, consequently, do not avail themselves of the health care system.

Most Americans have some form of health insurance. However, it may be limited by maximum dollar expenditures and/or scope of covered services. Medicare and tax subsidies help pay for these extraordinary expenses, however, there are over thirty-five (35) million Americans who have limited or no health care insurance. There are also thirty-six (36) million Americans with disabilities. Of this latter group, approximately one-third do work and receive no public assistance. One quarter are receiving public assistance but are not working. The balance receive public assistance and 5% of them work. However, the nature and extent of their health care coverage is not well known.

Studies show that half of those who spend more than $5,000 per year for medical expenses are in health care institutions. One point three percent (1.3%) of the population accounts for more than 50 percent of all charges in short stay hospitals, and this pattern holds across all age groups. If data on long stay institutions is added, approximately 2% of the population accounts for over 60% of hospital and institutional care expenses each year. High family costs tend to be concentrated on one family member. Also, high cost illnesses are repetitive and result in repeated hospitalizations, and, these costs began before and continue after the year measured in the studies. Disabled Medicare beneficiaries use nearly twice as many Medicare services as the elderly and use them more at every expenditure threshold.

Caucus participants have found that rehabilitation patients easily exhaust their health care coverage or require extensive services which are not covered. In either event the patient and the family, if a family support system exists, are confronted with excessive financial burdens for the services. If the patient is unable to pay, facilities must decide under what conditions to provide the services. Many non-profit facilities are required by their charters to serve patients without regard to their ability to pay which may cause excessive financial burdens for a facility.

A brief survey of insurance coverage by the National Association of Rehabilitation Facilities (NARF) revealed that a patients rehabilitation needs depend upon whether the patient is hospitalized, since nonhospital custodial or skilled nursing home care or extensive home health care is frequently not covered except under Medicaid and partially covered under Medicare. This limited coverage, which is dependent upon hospital stays in most policies, although not recently for Medicare, does not address chronic illnesses or disabilities which require intermittent hospitalization and home health or nursing care. For example, under the current Medicare system, physical therapy services for a stroke patient are fully covered as long as that patient remains in the hospital. Once the patient is discharged, coverage for physical therapy services is still available, although in less than comprehensive form. The beneficiary is only entitled to home physical therapy visits if he or she is completely homebound, while outpatient visits to an independently practicing physical therapist are currently covered only up to $500 per year as is the case for occupational therapy. However, there is no coverage for independently practicing speech-language pathologists. Physical therapy, occupational therapy and speech-language pathology services are limited to hospital outpatient services, comprehensive outpatient rehabilitation facilities and rehabilitation agencies.

Once the patient's level of physical function increases, and the patient is no longer deemed to be "improving," Medicare payment is discontinued, as therapy after this point is defined as "maintenance," and is disallowed. Without this "maintenance" therapy, however, many patients will regress and lose function, causing them to become less independent and, in some cases, leading to recurrence of an acute episode and the need for expensive inpatient treatment. Additionally, the NARF study highlighted the problems that exist under commercial health insurance with coverage for rehabilitation services.

B. A TYPICAL EXAMPLE

The Washington Post (week of June 9, 1988) carried a series on the experience of a Virginia family when their 20 year old son was in an automobile accident and suffered severe head injuries. The articles traced his care from the shock/trauma center through his rehabilitation. The series highlighted all the emotion, time and money which a family experiences when a member suffers a catastrophic illness.

The second article highlighted the problems the family faced when he was ready for rehabilitation. When the family sought to have him moved to a rehabilitation unit in a local hospital they discovered that their health care coverage through the Federal Government, the health maintenance organization, Kaiser Permanente, did not cover rehabilitation services. The father was employed by the Federal Government. The son had been in a trauma center hospital for 78 days before being transferred. According to a NARF study, NARF Position Paper on a Prospective Payment System for Inpatient Medical Rehabilitation Services and A Study Regarding A Prospective Payment System for Inpatient Medical Rehabilitation Services: A Final Report, December 1985, the range and length of stay once a patient is referred for rehabilitation services for a head injury is from 12 to 80 or more days. Again, this is only for the inpatient hospital rehabilitation stay and does not account for the services needed after discharge from the hospital.

The bills for the inpatient care were very high. The shock/trauma charges alone were over $100,000. The family had never worried about bills before, assuming that the medical insurance through the father's employment covered all possibilities. The family, like many families, had no reason to believe that they would find themselves without coverage. Once the son began to emerge from a coma and qualified for a rehabilitation center, Kaiser Permanente first stated it would pay none of the cost, estimated at $18,000 per month, for rehabilitation near their home. The family, upon reviewing the benefit booklet, found at the very end of the list of exclusions under "What Is Not Covered" an exclusion for "the services of a rehabilitation center." These types of exclusions are not uncommon in commercial insurance coverage and are particularly common with HMOs. Frequently, a company will say that the services of a rehabilitation hospital are not covered because the hospital does not meet the plan's definition of a hospital, usually because it requires surgical facilities on the premise and does not recognize a contractual arrangement with another local facility. Another frequent type of exclusion, cited in the article is that the insurance does not cover care which is primarily for rehabilitation, convalescence or custodial care. However, this particular health plan would cover 100 days a year if the son were in a nursing home as opposed to a rehabilitation center. The family's only other option was to qualify for Medicaid but the only state approved Medicaid facilities were 100 miles away.

After a second opinion and repeated interviews the HMO agreed to pay for four more weeks of care in a general hospital while the son received speech-language pathology services and physical therapy. It still would not promise to pay for long term rehabilitation once the son left the hospital. Eventually it agreed to pay for only 60 days of rehabilitation care in the rehabilitation unit of the local hospital.

When interviewed, the company stated that it tries to predict how many catastrophic bills it may incur and, while it may be willing to absorb "our fair share of cases like this," it did not want to price its product out of the market and suggested that families obtain major medical policies for an additional monthly premium. The Post noted that major medical policies can be difficult to obtain and that Kaiser and most HMOs simply do not offer them.

Over a year after the injury, the son continues to make progress in the rehabilitation unit. After intervention by the government, the hospital was qualified by the state to treat Medicaid recipients. One wonders why obtaining coverage had to be so difficult!

C. UTILIZATION AND AWARENESS

An SRI Gallup report, commissioned by NARF and the American Hospital Association Rehabilitation Section, addresses public awareness of medical rehabilitation. The study found that consumers, payors and physicians do not realize the full benefits of rehabilitation services. Thirty percent (30%) of Americans reported that they, their spouse, parents or children had had a serious illness or injury such as a brain injury, stroke, amputation, or birth defect. However, two out of every three respondents reported that treatment for these serious physical problems had not, to their knowledge, included rehabilitation services. The reason for this being that the condition was "not serious enough" to warrant rehabilitation services. This rationale implies that once a physical problem is no longer considered "life-threatening," then the need for extensive medical assistance no longer exists.

This reasoning, coupled with the lack of awareness on the part of the consumer, payors, and physicians, as well as the restrictive policies of the insurers, leaves one with little doubt as to the extent of this problem.

Existing health care coverage has a high institutional bias. If services are to be covered, they are generally available only when a patient remains in a hospital setting. Hence, there is often inappropriate institutionalization and unnecessary care for some patients, and inadequate or unavailable services for others. After hospitalization, a patient is frequently referred for outpatient services, home health care or skilled nursing care. When a patient's coverage is exhausted or the patient needs less intense services which are not covered such as nonskilled services, simple custodial care, respite care or homemaker-health aide care, these services are withheld. The patient's health may decline, requiring readmission to a hospital and the cycle begins anew. So do the costs. These problems are becoming increasingly acute as our nation ages and as medical technology saves more people, but leaves patients impaired and requiring extensive rehabilitation services.

The report of the Secretary of Health and Human Service's Task Force on Long-Term Health Care Policies and the Brookings Institution report highlight several issues:

1. The elderly and non-elderly disabled prefer to remain in their own homes as long as possible and be cared for by relatives. Only about 21% of the disabled elderly were in nursing homes in 1985.

2. The vast majority, nearly 90% according to the Brookings Institution, of those who are not in nursing homes, received assistance from relatives and friends sometimes supplemented by paid services. Studies have shown that usually these caregivers are female--the wives, daughters, or daughters-in-law.

   The personal, emotional and financial costs to the family and other friends and relatives in providing this care is sometimes astronomical.

The nation's focus should be on reducing dependency and allowing people to maintain themselves in their own homes. In many cases, rehabilitation is the key for doing this. Therefore, in looking at the requirements for comprehensive and long-term care, the undersigned organizations recommend that this Commission first look at providing adequate rehabilitation services as a way of avoiding permanent custodial costs.

II. MEDICAL REHABILITATION AND THE LONG-TERM REHABILITATION PATIENT

A. Role and Goal of Medical Rehabilitation

The goal of rehabilitation is to restore patients to their optimal functioning, thereby reducing dependency. Nonetheless, many rehabilitation patients, particularly (but not exclusively) the elderly, require continuing care services following or in support of the care rendered in rehabilitation facilities. Rehabilitation facilities and professionals often face very hard choices in dealing with the needs of their patients because they need long-term rehabilitation services and, because of the lack of coverage for such services.

Rehabilitation facilities and professionals serve people suffering from major illnesses or the results of accidents. For example, there are over 10,000 people with spinal cord injuries per year and the majority are the result of automobile accidents. There are between 700,000 and 900,000 head injured people per year of which at least 10% (70,000) are considered severely traumatically brain injured. Of these, over 50% are the result of automobile accidents.

Rehabilitation specialists also treat the elderly who suffer from strokes, arthritis, hip fractures, heart attacks, pulmonary and cardiovascular diseases, and neurological and musculoskeletal diseases. These individuals require extensive comprehensive services both from the time of the injury or illness, frequently through outpatient care, home health, adult day health care, residential living care and, in some cases, continued support on a daily basis. These programs have significant costs attached to them. As a result, facility administrators and financial officers face the personal, emotional, and financial trauma that occurs when our existing health care payment system does not help these special patients. These patients include the elderly, as well as non- elderly with disabilities.

Rehabilitation integrates medical and social services. There are over 700 rehabilitation hospitals and units, 160 comprehensive outpatient rehabilitation facilities, 1,300 rehabilitation agencies and other outpatient providers and 10,000 home health agencies providing rehabilitation services throughout the country.

The primary function of such facilities is to provide diagnosis and treatment of patients for specified medical conditions both surgical and non-surgical. The average length of stay in a rehabilitation hospital or unit is longer than in the acute care setting because the objective is restoration of impaired functions which follow serious disease or injury. The ultimate objective of rehabilitation is functional independence. Once a patient is released, many require outpatient and home care services to continue the rehabilitation process. Rehabilitation can minimize the need for institutionally based long-term care, although some people with disabilities require continuing institutionalization when home and community care is inadequate or when the severity of their disability requires it.

B. Cost-Effectiveness

While the emotional benefit of personal independence may not always be measured in dollars, psychological, physical and financial independence can. In terms of cost-effectiveness, rehabilitation ranks favorably as an alternative to extended institutional acute care. Research shows that the average costs for rehabilitation are two-thirds that of acute care. For example, early rehabilitation saves an average of $6,404 for each surviving stroke patient fortunate enough to receive it. In fact, cost studies of stroke rehabilitation show considerable return on the investment in services. A person who is not rehabilitated costs $92,736 in 1980 dollars more to support than a rehabilitated patient living at home. The average cost of rehabilitating an individual who has had a stroke is $8,000 to $11,500 in 1980 dollars. This results in average savings of $81,250 to $84,740, again in 1980 dollars. (The Cost Benefits of Stroke Rehabilitation, NARF, Washington, D.C., 1980)

A recent survey by the Health Insurance Association of America concluded that for every dollar spent on rehabilitation, $11.00 is saved in other benefits that would have been paid to the affected individuals.

Other studies have shown similar results:

- A 1981 study by the Insurance Company of North America concluded that in long-term disability cases, for every dollar spent on rehabilitation, $17.00 is saved in other benefits that would have been paid to the beneficiary.
- In 1981, Natisco Rehabilitation Management, Inc., a case management company, estimated that for every dollar spent on rehabilitation, $12.68 was saved in claim costs.
- Several studies on spinal cord injuries concluded that for every dollar spent on rehabilitation, $3.00 to $6.00 is saved.

In order to take full advantage of rehabilitation's cost-effectiveness coverage for these services must be extended to all settings.

III. RECOMMENDATIONS

The NRC supports services that can be delivered at home or through community-based organizations, such as rehabilitation facilities, or by practitioners of rehabilitation services, thereby allowing people to live in as independent a setting as possible. This is simply the more preferable alternative for most individuals. To this end, the NRC has the following comments for the Commission to consider in fashioning its report pertaining to needs of the elderly and people with disabilities:

A. Coverage

Public and private programs should provide coverage for persons with disabilities and not exclude them due to preexisting conditions, or require unreasonable waiting periods. For example, persons with disabilities who are eligible for Social Security Disability Insurance must wait two (2) years before receiving Medicare. This is after waiting five months before being able to apply for benefits. According to the World Institute on Disability, as many as one third of the SSDI beneficiaries have no health care during that two-year waiting period. This lack of coverage also includes lack of any Medicaid coverage. This is a crucial time period for a person with a disability as this is when the most benefit from rehabilitation services is usually realized. The NRC recommends that the two-year waiting period be eliminated.

Any final recommendations should assure coverage of the needs for all populations including the non-disabled elderly, as well as the potential long-term care needs of the poor, working poor, unemployed and employed.

B. Eligibility

The NRC recommends to the Commission that eligibility for any program not be triggered by age and/or resources (income and other) but by ability to perform activities of daily living, mobility and communcation. Several bills in Congress currently take this approach.

C. Objectives

The objective of any program should be to allow the elderly or non-elderly people with disabilities to continue to live a life of dignity and of the highest quality with an emphasis on independence, autonomy and responsibility.

D. Family Support

Support from the family and other informal systems should be encouraged. For example, the health of an overburdened family member should not be jeopardized due to not having home health services or the benefit of respite care.

E. Benefits

Benefits should cover a comprehensive, defined spectrum of appropriate medical rehabilitation, and social services, both institutional and home- or community-based, without financial bias in any direction. The traditional medical model does not serve all the needs of the disabled. Effective long term care also require social services in order to be truly beneficial. Any final recommendations should recognize and cover the complete spectrum of the patient's rehabilitation needs. People who do not receive such services quickly deteriorate and often end up being readmitted to a hospital or a nursing home thus incurring additional costs to the system. For example, HHS studied hospital readmissions, comparing homebound chronic obstructive pulmonary disease (COPD) patients who had received respiratory therapy rehabilitative services with those who had not received such therapy. Hospital readmissions rate for those receiving the rehabilitation therapy was .48/patients/year. For those without the rehabilitation the readmissions were 1.28/patients/year.

This continuum of coverage should be in addition to, rather than in replacement of, existing benefits and not used as a trade-off for, or limitation on, other benefits.

A comprehensive system should include the following services which are not included in current programs or policies: assisted devices and related services, respite, adult day care, homemaker-health aide, and psychosocial rehabilitation services. NARF and National Easter Seal Society members which run adult day rehabilitation programs note the annual cost of such programs ($12,500 per year average in New York City) is a considerable savings over the cost of a skilled nursing facility ($58,400 per year in New York City)-- almost a five-to-one savings. We also urge the Commission to look into such issues as nutrition, transportation, and housing, particularly for the non-elderly with disabilities.

F. Continuity of Care

Continuity of care and coordination of appropriate services must be ensured. For example, case management is an indigenous part of the traditional medical rehabilitation model and should be included in the Commission final recommendations. Such case management must be conducted by people with training in rehabilitation services.

G. Evaluation

Each person seeking care should have an initial, multidisciplinary evaluation of medical and functional status which is periodically reviewed. That is, the patient's ability to perform all tasks of daily living should be established at the time of application for benefits to help in determining eligibility, therapy and placement.

H. Financing

Inadequate funding will simply support a haphazard and ineffectual service delivery system. A combined public and private sector approach is the most reasoned one. This is contemplated in part in the Brookings study. It does have the drawback, however, of being economically determined, usually by income and/or employment status.

We recommend the following options for financing long term care services and programs:

* promoting long term care insurance policies which have appropriate standards
* requiring reasonable cost-sharing, co-pay and/or sliding scale fees
* re-examination of the national budget priorities
* providing a check-off on the income tax form to establish a public fund for long term care (i.e. 1.00 or other amount)

Representative GRADISON. And we thank you, Ms. Zollar. Thank you very much. Mr. Balog will inquire.

Commissioner BALOG. Mr. Chairman, I'd like to ask a question of Mrs. McSteen. In your comments, you talked about the Danish system. You talked about no means-testing, yet the Danish system I think is means-testing, which you cited as a possible way of doing it. In other words, 60 percent of all of the Social Security payments and then 60 percent of other income. That would seem to be means-testing.

Ms. MCSTEEN. It is in effect a way of allowing the nursing home residents to pay as much as they can for the service. As I understand it from their system, part of that rationale is really because that enhances the individual self-esteem, so it is done as much for the individual as anything else.

Commissioner BALOG. The other question, if I may, Mr. Chairman, in your testimony, you talked about a poll of your members in which 61 percent of them would be willing to pay the Medicare catastrophic surtax if the benefits included long-term care. Maybe the problem—I'm trying to probe as to whether or not that is representative of other elderly persons. Am I correct in understanding that it was the benefit that was the problem, not the means of raising the money?

Ms. MCSTEEN. It was a combination of both, you're right. It was a deep concern on the part of seniors that this particular coverage did not include custodial, long-term care, and that it was not broad-based financed. It was a dual concern that they had. With the name catastrophic, many people believed that it truly was custodial nursing home care that would be provided.

I think part of that goes back to the problems that we've talked about this morning in lack of communication. I think what has just happened really illustrates that we must listen and we must bring into the picture the viewpoints of all the people concerned as we move toward a solution that will resolve the problems.

Commissioner BALOG. We heard in the last panel how we should take steps in this direction. We can't get the global solution all at once. The catastrophic bill that was turned down was a step in that direction. It surely wasn't everything that everybody wanted, but having turned down the step, we may have taken a couple steps backward. I'm kind of curious as to why your groups weren't there lobbying for the steps forward.

Ms. MCSTEEN. The national committee, while the Catastrophic Act was just in discussion stages, was there and was making an effort to lobby.

Commissioner BALOG. Thank you.

Representative GRADISON. Dr. Davis will inquire.

Commissioner DAVIS. Thank you, Mr. Chairman. I'd like to ask Ms. McSteen also. I was intrigued with your suggestion that college students might be helpful in home care on a part-time reimbursable basis. Do we have a model in this country for this? You mentioned that again, in Scandinavian countries, it is being used. Is there a model here that we might know about?

Ms. MCSTEEN. There is not a model of any significant size that I'm aware of. I would need to research and give you that information which I will be glad to do.

Commissioner **Davis**. If you would and also some information on the Scandinavian experience with that would be very helpful to us.

Ms. **McSteen**. Thank you.

Commissioner **Davis**. Is your impression that it is pretty widespread in the Scandinavian countries?

Ms. **McSteen**. The use of the college students, no, I don't know that for a fact. I think it has gained momentum in thought in this country simply because it should help the intergenerational problem as well. As more and more colleges turn toward work study programs and practical approaches to preparing for the future, it seems a golden opportunity for us.

Commissioner **Davis**. I come from an area that has many universities and a lot of students that this might be very applicable and quite helpful. Thank you. If you would get us that information.

Ms. **McSteen**. I will get it for the record.

[The information referred to follows:]

NATIONAL COMMITTEE TO PRESERVE
SOCIAL SECURITY AND MEDICARE

2000 K Street, N.W., Suite 800
Washington, D.C. 20006

(202) 822-9459
FAX # (202) 822-9612

FOLLOW-UP COMMENT TO QUESTIONS ASKED MARTHA MCSTEEN AT THE PEPPER COMMISSION HEARING OCTOBER 5, 1989
OPTIONS FOR LONG-TERM CARE

Dr. James E. Davis: Regarding college students serving as homemakers in Denmark:

Q. Are there model programs here in this country?

As far as we know, no model programs exist in this country. There may be informal attempts here and there. For example, some years ago, Barnard College, New York City, had a student-run program called SHE - Students Helping Seniors - where Columbia University students performed chores for seniors and charged them directly.

We are aware of an AoA proposal a few years ago for a student-senior project in the Washington, District of Columbia area. The proposal called for linking students from Catholic University, University of District of Columbia and George Mason University with seniors needing help with chores and shopping. The students would get paid about $4.50 per hour. The senior would pay whatever they felt they could afford. No questions would be asked about income. The proposal was not funded.

The thought behind linking students with seniors to perform homemaker services is not to create a pool of lower-paid workers that would take away jobs from professional homemakers. Rather, students would fill in the gaps and would be paid no less than minimum wage.

Q. Is the use of students as homemakers widespread in Denmark?

In the cities fortunate enough to have universities or other institutions of higher learning, it is common. Students are especially used to fill in when the regular homemaker goes on vacation or is sick. In Denmark, everyone has a minimum of four weeks paid vacation.

In the 1970s, students often took jobs as homemakers which required minimal training. However, in recent years, jobs as homemakers have become a profession requiring about a 6 week training program and homemakers must be unionized. If students want to perform these jobs on a regular basis, they must go through the training and join the union. The minimum wage in Denmark is around $8 per hour. A beginning homemaker makes at least minimum wage if not more.

Mr. James Balog expressed interest in the Danish system of beneficiary copayment for nursing home stays. These are additional comments.

Nursing Home beneficiary copayments in Denmark

Nursing homes in Denmark are publicly owned and run by the counties. Most of them have private rooms and private bath. Residents are permitted to bring their own furniture and they do not sleep in hospital beds. The cost of running the country's 50,000 nursing home beds is paid for by general revenue and beneficiary copayments. Residents pay for their nursing home stay with their Social Security check less a monthly allowance. If there is other income, residents pays 60% of such up to the cost of the stay. Assets are not touched.

Denmark has placed a stop on the development of new nursing home beds and are instead using resources to build more protected housing for seniors. These are apartments with access to congregate meals, homemaker services and home health services according to need. The complexes also have a few sick beds or nursing home beds if a resident needs more extensive care.

A commission is currently studying the fairness of the nursing home allowance system. Some people believe that paying almost the entire Social Security check, takes away from the residents' sense of decisionmaking and control. Demonstration projects are trying to determine if a system would work that allows residents to take more control of their money. They would receive a larger allowance and out of it pay for various services such as meals, laundry and other essentials.

Commissioner BALOG. A question for Ms. Zollar. You talked about a checkoff system, both in your verbal testimony and also in your written testimony. In your written testimony I noticed that you talked about a checkoff system on each income tax return of a dollar or some other amount. I don't know how many tax returns there are, but I can't imagine there being more than about 100 million of them, so—but the numbers that one would need for a significant approach to the funding would be more like $500 to check off, so I'm kind of curious about your checkoff system. How much do you think might be raised through that approach?

Ms. ZOLLAR. I think when we were discussing this option among our coalition, we came up with the idea based on the checkoff for the public campaign fund. I think some of the numbers kicked around the table at this time, and I would ask you not to hold me to this as an accurate statement, were in the range of only several tens of millions.

I realize to finance such a program is infinitely more, however, because financing seems to be where we cannot come to consensus among any group at any table, that we are reaching for new and more different ideas that would show an individual willingness on a volunteer basis to finance this cause. That was one we came to.

Commissioner BALOG. I think that all of us in this field come to the problem of how to agree on financing it. We agree on the needs for sure, but clearly the financing is the main problem we all face and one that we need more answers to.

I think as Congressman Gradison said in his opening remarks, the needs are there. Everybody is quite aware of that.

Representative GRADISON. On behalf of the Commission, I thank all the members of this panel and at this time, call up the third panel, Dr. Paul Willging, Sheldon Goldberg, Mary Suther, and Lois Evans, and we'll ask Dr. Willging to lead off.

STATEMENT OF DR. PAUL R. WILLGING, EXECUTIVE VICE PRESIDENT, AMERICAN HEALTH CARE ASSOCIATION

Dr. WILLGING. Thank you, Mr. Chairman. I am Paul Willging, the executive vice president of the American Health Care Association. I am representing over 10,000 facility-based long-term care institutions in this country with some 1 million residents in those institutions.

I'm not absolutely sure, Mr. Chairman, that given yesterday's vote in the House, this is an auspicious or inauspicious State to be holding a discussion of long-term care coverage and financing in this country.

There was a small benefit within the catastrophic bill with respect to skilled nursing benefits. That, along with the rest of the bill, was wiped out by House action. Despite that action, nothing has changed with respect to the demographics in this country. We will not repeat them, but we know that those most in need of long-term care services, those 85 years of age and older, will quadruple over the course of the next 4 years.

We know that given the House action the primary, almost exclusive, public funding source for long-term care in this country remains the Medicaid Program, a funding source which has perhaps as its most noted characteristic, that it asks people to degrade and demean themselves before it kicks in in terms of the benefits available to that population.

I think I would prefer to focus in terms of yesterday's vote by the House on what we have learned as a result of the debate over the catastrophic bill over the course of the past few months, particularly in terms of some basic principles. If anything, that debate and that vote has, in my mind, emphasized some of those principles. Principles which cannot be forgotten as we try to restructure our approach to long-term care financing and move back on a course which will perhaps at some point, either earlier or later, give us a program which is more in tune with the needs of our elderly population.

Clearly, we have learned that a public-private partnership is more critical than perhaps ever before. I think what I have seen in that debate is that the Government cannot and will not be expected to take on the primary fiscal load with respect to long-term care services. The individual must share that responsibility with the Government. I think within that same context, a principle in terms of freedom of choice is equally critical.

The Government should not be focusing on providing the entire benefit, the maximum benefit, all of the bells and whistles, but rather, focusing on the indispensable minimum benefit that needs to be provided and allowing an individual to augment, to supplement, to go beyond with respect to his or her own needs and desires.

I think we have also learned in terms of a third principle that we desperately need a dedicated funding source and system of taxation if we are to fund such a benefit, a long-term care benefit, that is not subjected year in and year out to the kind of debilitating debate in terms of financing that we have seen over the course of the past few months.

Finally, and we have learned this not only in terms of the debate over the past few months but also in terms of our 20-some year experience with Medicaid, we need to pay attention to financing and reimbursement systems to make sure that the care provided the beneficiaries is driven as much, if not more, by the needs of those beneficiaries, than by fiscal vagaries, either at the Federal level or within the States.

I think these principles, at least in my own mind, are even more critical given the discussions over the past few months with respect to catastrophic legislation. What I think we have also determined and I do believe that it is unfortunate, but to quote Chairman Rockefeller at a reception for the public television program, Can't Afford to Grow Old, some 1½ weeks to 2 weeks ago, as he spoke to those attending the reception—if we cannot deal with a $6 billion problem, how can we be expected to deal with a $60 billion problem?

I think that has unfortunately set back the timetable for long-term care and forced us to recognize that for the foreseeable future, we are going to continue, whether we like it or not, we're going to continue to utilize the Medicaid Program as the primary public funding source for long-term care. I think that is unfortunate, but I think it also suggests that there are some things we can and should do immediately, if that is going to be our primary funding source.

Speaking from my past experience as Deputy Administrator of the Health Care Financing Administration, I was always amused by an inherent conflict of interest that exists in this country in terms of funding long-term care through Medicaid. We have State officials who submit reimbursement plans for the Federal Government, whose primary purpose is not the needs of the patient, but the needs of budgetary stability.

Those reimbursement plans are submitted to the Federal Government, whose officials—I was one—were concerned not primarily with the needs of the patient served, but with Federal budgetary constraints.

We would propose that at a minimum under Medicaid, we sort out this inherent conflict of interest by establishing an independent commission representing consumers but not beholden to them, representing providers but not beholden to them, representing State and Federal government but not beholden to it, which will at least guarantee that the requirements for care are matched by the resources made available by the State.

With that mechanism, at least, Mr. Chairman, I think we can begin to sort out the problems of the Medicaid Program. Thank you very much.

[The prepared statement of Dr. Willging follows:]

Statement of the
American Health Care Association

TESTIMONY OF PAUL R. WILLGING, Ph.D.
EXECUTIVE VICE PRESIDENT
AMERICAN HEALTH CARE ASSOCIATION

BEFORE THE PEPPER COMMISSION
UNITED STATES BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE

October 5, 1989

ahca
American Health Care Association 1201 L Street, NW, Washington DC 20005-4014 (202) 842-4444

For Further Information Contact: David R. Seckman
202/898-2857

TESTIMONY OF PAUL R. WILLGING, Ph. D.
EXECUTIVE VICE PRESIDENT
AMERICAN HEALTH CARE ASSOCIATION

BEFORE THE PEPPER COMMISSION
UNITES STATES BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE

October 5, 1989

Thank you very much, Mr. Chairman, for this opportunity to testify before the Pepper Commission. I am Dr. Paul Willging, Executive Vice President of the American Health Care Association (AHCA). We are the nation's largest organization of long term care providers, representing nearly 10,000 licensed nursing homes. Together they care for approximately one million frail, elderly and chronically ill persons.

AHCA has a very strong interest in working with the Commission on development of recommendations for a national long term care delivery and financing policy. We are committed to accessible, affordable, and quality health care for our nation's elderly and chronically disabled population. Long term care providers have a unique perspective on these issues. We hope our views and recommendations will make a significant contribution toward the Commission's goals.

Reform of long term care financing represents a tremendous challenge for our nation, especially in an era of rising concern over the deficit. While there are many options to make affordable health coverage available for all Americans, a consensus will not be easy to achieve. Yet, as I heard one of the Commission members remark recently, "If we are timid, this issue is not going to be addressed." It is AHCA's intention to outline a series of actions which we feel are necessary if this country is to advance toward a viable health care financing policy.

Let me begin by saying that long term care is the most likely catastrophic illness facing elderly individuals and families. The primary out-of-pocket health expense of the elderly is for long term care, costing more than hospital and physician care combined. This fact becomes highly significant when one considers the "graying of America." It is well known that, within fifty years, the portion of the population over age 65 will have doubled, and the portion over 85 will have quadrupled. In a little more than a decade--by the year 2000 - the number of the so-called "oldest old" will have grown to five million. This group--the 85 and older population--is most likely to need nursing home care. More than a fifth of these people are now living in nursing homes, and another fifth who do not live in nursing facilities require some type of long term care service.

These figures are especially troubling when one considers the cost of nursing home care, which averages $23,000 per person per year. How are such expenses paid? Most of the elderly mistakenly believe that Medicare will pick up the bill. Many younger people believe, equally incorrectly, that private insurance is a primary source of coverage. In reality, patients and their families pay for half of the nation's $40 billion annual nursing home bill. Prior to enactment of the Medicare Catastrophic Coverage Act, Medicare picked up about 2 percent of those costs, while private insurance covered less than that.

Clearly, neither Medicare nor private "Medigap" supplemental plans were intended to pay for long term care. Medicaid has thus emerged as the major governmental payor for nursing home expenses. Before passage of the Catastrophic Act, Medicaid paid for approximately 40 percent of those costs.

The biggest problem with this system of health care financing is that it is dehumanizing. By its very nature, Medicaid forces people to spend their life savings in order to qualify for benefits. Patients and spouses become impoverished, which is a degrading experience. The fact is that one-half of Medicaid dollars for nursing home care is spent on behalf of persons who entered the facility as private paying residents. As providers, AHCA members see this unfortunate scenario take place far too frequently.

Our complaint with the current long term care financing system is not just that it is a poorly organized patchwork of government programs and private funding sources. At bottom, we feel it is demeaning...driven primarily by fiscal concerns rather than patients' health needs. AHCA would like to offer the Commission our ideas for improvement.

Allow me to highlight eight principles for establishing a new long term care financing policy. These were developed by the leadership of AHCA and represent our fervent desire for change. Some of the steps can be taken in the near term, while others are more likely to be accomplished in the future:

1. AHCA recognizes the importance of a health care continuum, involving patients, family and friends, community care centers, hospitals, residential facilities, and nursing homes.

2. Private payments and private insurance should have as large a role in a national long term care financing system as possible.

3. AHCA supports a public/private partnership to effect the delivery and financing of health care.

4. Several improvements should be made to Medicare and Medicaid, especially to make the latter more uniform and less degrading to beneficiaries.

5. Congress should utilize a dedicated tax to help finance long term care.

6. AHCA supports retention of the Medicare skilled nursing facility benefit.

7. In order to address the critical nursing shortage facing providers, nursing homes must be able to pay their nurse personnel competitive salaries.

8. AHCA proposes the creation of an independent Nursing Home Payment Commission to review and approve state Medicaid payment systems, assuring their consistency with the standards set for long term care providers.

1. IMPORTANCE OF A HEALTH CARE CONTINUUM

AHCA recognizes that families should continue as the bulwark of the nation's long term care delivery system. Currently, 70 percent of care is provided through this informal part of the health care continuum. AHCA believes that Congress should encourage personal savings for long term care needs and support the provision of informal caregiving that will allow elderly persons to remain at home as long as feasible. We therefore support:

a. A "respite care" option under Medicaid to provide limited nursing home care as a respite from caregiving. This would prevent family members' burnout, and delay, if not prevent, the patient's institutionalization.

b. Elimination of restrictions on using Individual Retirement Accounts as a means of financing long term care. Specifically, a deduction should be allowed for contributions made beyond age 70 and a half. Additionally, the mandatory distribution age of 70 and a half is too early, considering that the typical nursing home patient is admitted at age 80.

2. LARGER ROLE FOR PRIVATE PAYMENTS AND PRIVATE INSURANCE

Despite increased interest, private insurance is still in its infancy with regard to meeting the nation's long term care needs. At the moment, the burden clearly rests on Medicaid and the elderly themselves. AHCA believes that individuals should be encouraged to finance their own care as much as possible, through their own resources and via private insurance. We therefore support:

a. A comprehensive effort to improve consumers' awareness of long term care financing. The nation must combat the widespread misconception that Medicare and private insurance are primary payors.

b. Insurance companies' development of long term care policies with reasonable deductibles and copayments, and less restrictive front-end exclusions and underwriting requirements. Private insurance, with reduced premiums, should be marketed to younger age groups to foster better planning for their long term care needs.

3. PUBLIC/PRIVATE PARTNERSHIP FOR HEALTH CARE FINANCING

AHCA envisions the development of a public/private partnership, much like Social Security and private pensions. Both sectors would take an active role in order to make the delivery and financing of long term care more effective. We support:

* A "stop loss" legislative approach that balances individual and family responsibility with an appropriate level of government assistance. Such a plan might, for instance, expand Medicare to cover nursing home care after a two or three year exclusionary period, during which beneficiaries would be responsible for their own care. Incentives might be built in to encourage employers and employees to purchase long term care insurance to cover the deductible period and patient copayments. Income related coinsurance might also provide assistance in the post stop-loss period.

The above plan would do two important things: create a strong incentive for the purchase of private insurance to cover the deductible period; and encourage insurers--with a defined period of risk--to make lower priced premiums available.

In 1987, the Brookings Institution studied the benefits of such a plan, called the Brookings/ICF Long Term Care Financing Model. This simulated a public nursing home insurance program under Medicare with a two year deductible and 10 percent coinsurance. At age 67, elderly individuals and couples were assumed to buy a private insurance policy to supplement their public insurance. Such a policy would cover a maximum of two years in a nursing home, providing a non-indexed benefit of $50 a day.

The Brookings analysis showed that in 30 years, some 70 percent of the elderly would be able to afford private insurance policies to supplement their public coverage. Brookings calculated that the combination of public and private insurance would account for 63 percent of total nursing home expenditures; would reduce Medicaid expenditures by 65 percent; and would reduce the number of Medicaid nursing home patients by 37 percent. Testimony to this effect was presented before the Senate Finance Committee on Health, which was examining long term care financing.

4. IMPROVEMENTS TO MEDICAID

Along with encouraging individuals to use their personal resources and buy private insurance, improvements in governmental health care financing programs are necessary. Medicaid is in need of changes to make it more uniform and less degrading to beneficiaries. AHCA therefore supports:

a. Application of a national income standard for Medicaid eligibility.

b. Establishment of a uniform federal "spousal maintenance allowance" (i.e. a portion of the institutionalized spouse's income) equal to 150 percent of the federal poverty line for couples. This would allow a patient and spouse to live in dignity while permitting the institutionalized spouse to qualify for Medicaid.

c. Congressional action to purchase long term care insurance premiums out of Medicaid, on a sliding scale, for persons in need.

5. DEDICATED TAX TO FINANCE LONG TERM CARE

AHCA believes it is appropriate to expect all taxpayers to shoulder the responsibility for meeting the nation's long term care needs. Our lengthening life expectancy--74.8 years at present--and the rapid growth in the 65 and older population mean that long term care will be a necessity for millions more Americans over the coming decades. We therefore support creation of a dedicated tax out of FICA to enable the public sector to better finance long term care.

6. RETENTION OF THE MEDICARE SNF BENEFIT

Before passage of the Medicare Catastrophic Coverage Act in 1988, the Medicare skilled nursing facility (SNF) benefit existed mainly on paper. After enactment, it became a bona fide benefit used by many elderly and disabled citizens. In removing artificial limitations, such as the three-day prior hospital stay and the "spell of illness" concept, Congress finally made benefits available to all those with legitimate medical needs.

According to the Health Care Financing Administration (HCFA), more than 500,000 beneficiaries will obtain a day of covered care during 1989. This figure demonstrates that the SNF benefit is being used, and, consequently, that many nursing home patients are receiving a higher level of care.

Unfortunately, Congress is under great pressure at the moment to repeal the entire Catastrophic Act, including the skilled nursing facility benefit. Repeal would put a tremendous hardship on thousands of patients who are deriving meaningful financial assistance in their chosen nursing home. AHCA urges Congress to retain the SNF benefit. Furthermore:

* We object to a reinstatement of the three-day prior hospital stay requirement. A person who has suffered a mild stroke or a hip fracture while at home--and who would receive appropriate care in a SNF-- not be required to spend three days in a hospital for the purpose of obtaining the Medicare SNF benefit. Likewise, for those patients already in a nursing home, being transferred to a hospital could be physically harmful.

7. PAYMENT OF COMPETITIVE NURSING SALARIES

Any proposals for comprehensive long term care must take into account the critical nursing shortage facing providers. In order to remedy this problem, nursing homes must be able to pay their nurse personnel salaries that are consistent with hospitals. Studies have shown that registered nurses in nursing homes earn an average of 35 percent less than their hospital counterparts. In order to care adequately for our nation's growing elderly population, nursing homes must clearly be able to pay their nursing staff competitive wages.

8. NURSING HOME PAYMENT COMMISSION

The adequate reimbursement of providers is an essential ingredient in any responsible long term care financing policy, since it ensures that an appropriate payment is ultimately delivered for appropriate care. To this end, AHCA supports:

> * Creation of an independent Nursing Home Payment Commission, whose task would be to compare state resources with the quality standards mandated for nursing homes. The commission would be empowered by Congress to review and approve the adequacy of state Medicaid reimbursement systems. Members of the commission would represent a variety of interests and have overlapping, multi-year appointments. Professional staff members would conduct the analyses and assist in determining if the state resources are in line with provider standards.

In conclusion, Mr. Chairman, AHCA believes that a number of steps are necessary--indeed critical--if our nation is to arrive at a coherent, fair, rational, and responsible long term care financing policy. As you put it so succinctly, "If we can't deal with a $6 billion SNF benefit, how will we deal with a $60 billion problem?" I have outlined for the Commission's consideration eight options formulated by AHCA's leadership. These are designed to move incrementally toward an overall policy that will satisfy America's health care needs.

We support a continuum in which individuals and their families, community care centers, hospitals, residential facilities, and nursing homes all play a vital role. We foresee the expanded use of individuals' own resources and private insurance; the development of a public/private partnership for long term care financing; improvements to Medicaid; adequate reimbursement for providers; and a dedicated tax so that all Americans share in the responsibility for each other's future. More than anything else, providers want to help bring about a system whereby patients do not have to become impoverished in order to qualify for benefits; and where we don't have to turn them away because of an inability to pay for care.

A century ago, America had a "manifest destiny": expansion across the continent. Today, I submit, we still have a manifest destiny. As we live longer and get grayer, we all must face the prospect of debilitation. Our task as a nation is to face this fact squarely and do what is necessary, what is humane, and what is right. I assure you, Mr. Chairman, that AHCA is committed to these goals and we stand ready to help the Pepper Commission in whatever way we can.

Thank you very much for the opportunity to testify today.

Representative GRADISON. And thank you very much, Dr. Willging. Mr. Goldberg?

STATEMENT OF SHELDON L. GOLDBERG, PRESIDENT, AMERICAN ASSOCIATION OF HOMES FOR THE AGING

Mr. GOLDBERG. Mr. Chairman, my name is Sheldon Goldberg. I'm the president of the American Association of Homes for the Aging. We refer to it as AAHA. I am proud to represent the religious, nonprofit, and fraternal providers of institutional care and community-based services across this country.

I represent institutions that provide nursing home and health care. They provide housing, continuing care retirement communities, and a broad range of community services all the way from home care to respite care and a number of other services. Today, in America, our members are providing service to approximately 500,000 in our residential programs and countless hundreds of thousands of persons in the community.

The challenge to this committee is tremendous. It is to focus and perhaps renew; to rise like the phoenix in terms of where we go from here after the stunning losses of the past couple of days. It is obvious to the most casual observer that there is a need to build a long-term care system that is comprehensive. There is no single service, whether it be nursing home or home care or community-based service, that meets the needs of all.

As people age or they become increasingly disabled, those changes in need vary dramatically. I am proud of AAHA's role in providing long-term care services. Some of our members predate the Constitution of the United States. I represent members that have been in existence for over 200 years. It is common for our members to have provided continuous service for 50, 100, and some have gone back prior to well over 200 years.

This Commission has a most difficult task, and perhaps it is made more difficult by recent history. Uniquely, the challenge to this Commission is that the issues will not go away. If anything, the issues will compound, becoming more important and more pressing. This is simply a function of the demographics of our society as it becomes increasingly aged.

It is critically important that we create a balanced public-policy approach to meet the needs of the elderly today, and those of the elderly in the future as well. The charge of this committee is to provide leadership. I don't think there has ever been a time, given the losses of the past few days, when we critically needed leadership more in this country to structure a health care system that responds to people.

It reminds me of what is going on in American corporate business today. It's a healthy sign—that is, strategic planning. Maybe strategic planning relates to the charge of this Commission. First, let's set the goal or the vision on where we are supposed to be going. Another part of strategic planning is to build a broad consensus—perhaps that is most evident today.

Second, let's make the incremental steps to get there. That's what I hope will result from this Commission. Our testimony speaks to the needs. I will not be redundant. I want to stress one or two issues, if I might, in the time remaining.

Primarily, there is the need for a continuum of care. It is not solely home care or solely nursing homes. It is not residential programs versus community-based programs; it is a combination of both. Any solution that addresses the problems of the elderly will have to address all of these.

In the time remaining, I would like to address one major point which I think has been discussed at length and what, Mr. Gradison you identified, is how we finance. I am very pleased with the focus of this discussion because there is a consensus. Consensus No. 1 has come from the consumers and providers and from Members of Congress and this Commission. A consensus that there is an emerging need for a public and a private partnership on how we address the solutions.

The solutions cannot be achieved by one sector alone. I'd like to focus my remarks specifically on that partnership. First of all, I believe the magnitude of the expenditures and the problems are going to require that there be a public-private partnership in terms of finding these solutions.

We believe very strongly that the appropriate role for the private sector will be a joint effort of individuals, employers, private insurers, and the Federal and State governments to begin to promote private markets for long-term care insurance. Individuals should begin to purchase long-term care coverage during their working years through employer-sponsored plans. And, where they do not exist, through the open market. These programs are developing every day.

Prefunding during working years could make private long-term care insurance affordable to the majority of persons in the future. Employers could provide access to long-term care insurance either by using a menu benefit program or by simply making these programs available to their employees through group benefits.

Private sector markets are growing rapidly. They require Government intervention because some of the products need improvement. They've got to respond to barriers of coverage, inflation, and other conditions in this area. We need Federal tax incentives in these areas as well.

There needs to be a minimum set of standards that insurance programs should respond to. It also is important to say that there is a critical need for the public sector. The Federal Government has the unique role of responding to those who simply do not have the money, the resources, are simply impoverished. They cannot buy these products for themselves.

Government must provide coverage to those who are impoverished and do not have these resources. It is through this joint approach in which we look at different age populations—those who have time to plan for long-term care services, the 50 to 65 range population, and those who may have the resources within the older populations—that we can respond and stimulate the private market so that they protect themselves.

Long-term care has been documented as a very insurable event. The insurance is not all that different from life insurance or health insurance or auto insurance, which are pretty much universal.

People purchase those to protect themselves. I believe long-term care insurance, if communicated properly to the elderly, will mean those who can afford it will be purchasing such products. We feel it is a partnership that has to go forward.

Mr. Chairman, we commend you on your work, your diligence, your dedication, and the important work at hand. Thank you very much.

[The prepared statement of Mr. Goldberg follows:]

A A H A

Statement by

Sheldon L. Goldberg
President
American Association of Homes for the Aging

on

Long-Term Care: Options & Financing

Before the

Pepper Commission

October 5, 1989

AMERICAN ASSOCIATION OF HOMES FOR THE AGING

1129 20th Street NW, Suite 400, Washington, DC 20036-3489 • 202 296-5960 • FAX 202 223-5920
Midwest Office • 911 N. Elm Street, Suite 228, Hinsdale, IL 60521 • 312 323-6755 • FAX 312 325-0749
Western Office • 5010 Aspen Drive, Littleton, CO 80123 • 303 795-5465 • FAX 303 794-0487
Northeast Office • 2801 Jefferson Court, Ambler, PA 19002 • 215 628-2232 • FAX 215 628-2515
Donald L. Gilmore, *Chairman* • Sheldon L. Goldberg, *President*

Mr. Chairman and members of the Subcommittee, I am Sheldon Goldberg, President of the American Association of Homes for the Aging (AAHA). AAHA is a national nonprofit association representing over 3,400 nonprofit facilities providing health care, housing, continuing care retirement programs, and community services to more than 500,000 older individuals every day. Many of our members also provide a range of community services, including home care, adult day care, respite care, and nutrition programs. The majority of AAHA homes are affiliated with religious organizations while the remaining are sponsored by private foundations, fraternal organizations, government agencies, unions, and community groups. With strong community involvement and long-standing community ties, AAHA members are committed to meeting the physical, social, emotional and spiritual needs of their residents in a manner which enhances residents' sense of self-worth and dignity and allows them to function at their highest levels of independence.

Mr. Chairman, I appreciate the opportunity to testify before the Commission today on behalf of our Association concerning issues related to the development of a meaningful long-term care program. Although your Commission faces a difficult task of finding ways to resolve the problems of access to and financing of health care services and long-term care, there are few tasks more important to our nation today.

In my testimony today, I would like to address three key issues regarding long-term care services: first, the need for a federal long-term care policy; second, the appropriate roles of the public and private sectors in covering long-term care; and finally, the requisite needed dimensions and parameters of an appropriate long-term care system, including financing.

NEED FOR A FEDERAL LONG-TERM CARE POLICY

During the previous briefings and hearings of this Commission, you have heard of the need for long-term care. I will discuss that need only briefly.

Currently, the United States has only one federal policy for handling the long-term care needs of its elderly and disabled citizens and that is Medicaid. Unfortunately, the elderly who require chronic care in a nursing home or in their own homes must spend all their finances on such care, until they have exhausted their own resources and "spend down" to Medicaid eligibility.

Clearly, the need for long-term care is growing. Nearly 1.6 million of America's elderly are now living in nursing homes, but that number will double in 30 years under current utilization patterns. Equal numbers of elderly citizens are estimated to be in need of home and community-based services in the future.

While increasing good health among the elderly means that more older people are active and able to take care of themselves, the prevalence of disability increases with age, and the fastest growing age group in our population is the group 85 and over. Thus the challenge we face is to provide the kind of chronic long-term care services needed by elderly individuals whose ability to perform basic activities of daily living (such as eating and dressing) has been impaired.

We know that the elderly would prefer to remain in their own homes as long as possible, and many are able to do so. Eighty percent of this nation's over-65 population remains at home, with outside help in some cases. Nearly 90 percent of the disabled elderly who remained in their own homes received assistance from relatives and friends, sometimes supplemented by paid providers. American families expend considerable time and effort in taking care of elderly relatives, with one study estimating that families provide more than 27 million unpaid days of informal care each week. Families often incur substantial physical and emotional strains in caring for their elderly relatives, yet federal health policy does little to support those families. A long-term care system must recognize and nurture the important contribution made by family members. AAHA believes that the modest respite care benefit enacted as part of the Catastrophic Coverage Act of 1988 (P.L. 100-360) should be improved by deleting the requirement of three months of unrelieved family care prior to eligibility. Families with no relief from the burdens of caregiving may be unable to manage three months of assistance and may be forced to place their relative in a nursing home. This is particularly true where the caregiver is also elderly. In addition, tax credits or tax deductions for caring for infirm elderly family members would also be positive incentives for families in which potential caregivers are available.

We also need to recognize, however, that the families in which a daughter or son stays home to take care of an elderly parent are dwindling. Our country is undergoing a transition from a society in which adult children provided the majority of care for the nation's elderly population, to a society where the cost of living usually requires that adult children work outside the home and few are available to become primary caregivers. For these families, professional caregivers will have to provide most of the assistance, with families assuming a secondary role. This transition has tremendous implications for facilities, personnel and financial resources, and those implications must be considered in the development of federal long-term care policy.

The Medicare home health benefit offers some assistance to those in their own residences, but it is an acute care benefit which requires a patient to be homebound and in need of part-time or intermittent skilled nursing care or physical therapy for illnesses which will respond favorably to treatment. Additionally, it does not cover the personal care needed by many of the elderly, and it is generally available for only very short periods of time. Many could remain in their own homes if chronic care home care benefits were available and affordable. Although AAHA supports the concept of the continuum of care and provision of services in the least restrictive setting, we must also emphasize that many elderly will continue to require nursing facility services.

The majority of spending on long-term care services is for the elderly who must be cared for most effectively in nursing homes. However, the cost of a lengthy stay in a nursing home exceeds the financial resources of most older people. While the Medicare Catastrophic Coverage Act provided some relief to prevent or delay spousal impoverishment, that step forward may be in jeopardy if the law is repealed. By spending their resources and assets to pay for care, many elderly become eligible for Medicaid. Approximately 50 percent of all nursing home expenditures are paid for by the elderly out-of-pocket. Medicaid pays for 47 percent of the remaining services, with Medicare paying for less than two percent and private insurance covering 1.4 percent.

Thus, Medicaid is the primary long-term care program in this country, and many elderly are seeking an alternative to impoverishment as the criterion for coverage of their long-term care needs.

ROLES OF THE PUBLIC AND PRIVATE SECTORS

National deliberations over expansion of Medicare coverage for catastrophic illness expenses have intensified the debate over who should pay for long-term care services. Considering the magnitude of expenditures required to fund chronic care services, few could disagree with the need to form a strong partnership between the public and private sectors in identifying solutions. It would seem that proposals to establish a national system of long-term care insurance are neither politically nor economically feasible at this time given the growing national debt. States' capacity to fund chronic care services are equally precarious with many states currently spending upwards of 40 percent of total Medicaid budgets on long-term care services.

Similarly, while long-term care insurance would be affordable to most individuals over the long run if pre-funded across a sufficiently large risk pool, in the short run, many older persons currently requiring chronic care services, or likely to need such care in the near future, do not have the financial capability to purchase private insurance protection. Thus the critical question regarding long-term care financing must center around identifying the most appropriate and feasible roles for both the public and private sectors.

ROLE OF THE PRIVATE SECTOR

Appropriate roles for the private sector will require the joint efforts of individuals, employers, and private insurers.

To ensure adequate financing in the future, individuals should begin purchasing long-term care coverage during their working years through employer-sponsored health benefit programs. Pre-funding of benefits over the entire labor force would make long-term care insurance affordable to the majority and ensure that no one individual would incur catastrophic expenses.

Employers have a responsibility to help employees obtain access to insurance protection for chronic care services. While few would dispute the potential liability faced by many employers for unfunded post-retirement medical benefits, employers can begin offering long-term care insurance coverage as part of a menu of employee benefits or through employee-pay-all programs. The Aetna and Travelers insurance companies have developed such policies and report a 15 percent participation rate of employees between the age of 30 and 50. The federal government should offer tax incentives to both individuals and employers to encourage working-age adults to begin prefunding their long-term care needs.

While private individuals and their employers must take responsibility for long-term care protection, private insurance carriers must also provide incentives for purchasing such protection by developing meaningful private insurance policies. Many existing policies are overpriced, offer little inflation protection, and establish barriers to coverage of services most preferred by consumers (i.e., custodial, home and community-based services). Many do not cover other desirable services, such as adult day care and respite care.

Long-term care insurance coverage is growing with the number of policies sold tripling in the past two years and the policies are improving. It would seem that the marketplace does not require tax incentives to offer the types of products currently available. Instead, any federal tax incentives should be tied to products which would meet minimum requirements for range of services and inflation protection. AAHA sees great promise in using a public/private partnership in funding long-term chronic care services. With first-dollar coverage from private insurance policies or out of pocket, federal coverage could become available after individuals satisfy an up-front deductible.

The success of this federal stop-loss approach depends, in part, on the availability of private long-term care coverage and individuals' willingness to purchase insurance to cover service utilization during the deductible period. AAHA supports legislation which would:

1. provide tax advantages to individuals in the form of tax credits for insurance premiums and tax-free withdrawals of income from IRAs for premium payments for federally-approved policies. Since nearly half of the elderly do not pay income tax at all, an alternative individual incentive could restructure the Medicaid criteria to establish a stop-loss coverage from further asset spend-down for anyone paying for an approved policy for a specified number of years.

2. provide employers with the same tax advantages for contributing to approved long-term care benefit plans as they currently enjoy for contributing for accident and health insurance;

3. create an exemption for interest earned on long-term care reserves of approved policies by insurance carriers.

These revisions of the tax code would make long-term care insurance a more attractive and sound opportunity for insurers.

The Commission may also wish to study several demonstrations which are allowing states to design and purchase long-term care insurance for Medicaid beneficiaries, such as the National Social HMO Demonstration and demonstrations funded by the Robert Wood Johnson Foundation in six states, in order to assess possible expansion of private market coverage.

Expansions of the incentives for private long-term care insurance should include meaningful consumer protection measures. We support efforts to prevent abuses in this burgeoning insurance market and to establish standards for long-term care insurance policies. Requirements for guaranteed renewability and prohibition of prior institutionalization as a criterion for service, would do much to resolve problems with current private long-term care insurance policies. The fundamental problem of a lack of indexing for inflation would remain, however, and we would urge you to consider whether Congress should require that benefits remain reasonable in relation to costs in the future, either by indexing for inflation or by paying a percentage of service costs.

One private sector option for integrating financing and delivery of long-term care services, which is growing in popularity, is the continuing care retirement community. Many communities offer life care services, ranging from independent living accommodations to nursing home care for their residents. Residents sign contracts for this extensive package of housing and health services, and pay an entrance fee and monthly fees. In return, the community assumes the financial risk of providing whatever services the resident needs for the remainder of his or her life. The continuing care retirement option has been pioneered by the not-for-profit sector, and we estimate there are now approximately 900 such communities throughout the country.

Many of our members are also exploring ways to provide this option to low- and moderately-low income individuals. Federal long-term care policy should encourage the growth and development of these alternatives.

ROLE OF THE PUBLIC SECTOR

The public sector should be responsible for a minimal long-term care benefit, which is to be supplemented by individual payments and private insurance coverage.

Implementation of a meaningful long-term care program may be many years in the making, and the system may need to evolve with successive aging cohorts. We believe that several approaches may be required to provide adequate and equitable long-term care coverage for different age populations.

One approach would deal with the elderly who have assumed that Medicare would cover their long-term care needs and have made no other plans, and who now find private insurance exhorbitantly expensive. Another approach would address the needs of the near-elderly in the 50-65 range, who may not be able to purchase adequate insurance to fully pre-fund their future long-term care needs. A more expanded long-term care benefit may be necessary for those groups of individuals. A less comprehensive approach would address the needs of those now in the working population who are able to plan and pre-fund their long-term care needs through private insurance.

In addition to a strong leadership role, and creation of incentives for private long-term care insurance coverage, the federal government's most important role is to insure the protection and safety of those most in need. The public sector must also provide expanded coverage for the impoverished and low-income elderly through either direct payment for services and/or subsidization of private insurance premiums. Public subsidies may represent an efficient form of assistance since the provision of private insurance could reduce pressures on public sector programs and reduce future increases in public spending through the elimination and/or reduction of the Medicaid spend-down provision. Public long-term care protection could be designed to provide coverage beyond a specified threshold, becoming effective at the point where an individual exhausts private insurance protection or where expenses become catastrophic. Federal coverage or subsidies may also be appropriate for those who are unable to obtain private insurance due to high underwriting risk as a result of advanced age or health risk.

The public sector should also improve coordination of federal programs of assistance to the elderly, including Medicare, Medicaid, Social Security, Title XX, aging and housing services to maximize the use of federal dollars and ensure that national policies are consistent.

DIMENSIONS OF A LONG-TERM CARE PROGRAM

I would like to turn now to our third area of concern: elements that AAHA believes should be considered in the federal long-term care program. Those elements must address eligibility, services, and financing for long-term care.

ELIGIBILITY

Benefits should cover all elderly individuals. Consideration should be given to expanded eligibility for both children and adults who are chronically ill or disabled, although such coverage should be tailored not to displace primary coverage through employers other insurance, or other programs. Eligibility for coverage of individuals under 65 should be phased in over a number of years. To be eligible for services, elderly individuals would have to be impaired in three or more activities of daily living, or suffer from dementia accompanied by behavior problems. The adoption of a three or more ADL threshold would limit the eligible population to 2.6 million of the 6.2 to 6.5 million persons who depend on others for help with ADLs. Eligibility must include those persons who require constant supervision as a result of dementias such as Alzheimer's Disease.

SERVICES

AAHA supports benefits which include a continuum of care in a variety of settings. Care should be available in the most appropriate setting, whether that is in the home, a congregate housing unit, a nursing home, an adult day care center or other appropriate facility. Benefits should be neutral relative to the site of care, that is, they should not encourage either institutionalization or home care in order to obtain more adequate coverage. Optimally, services to be covered should include, at a minimum, custodial nursing facility care, home care (including homemaker and chore services), adult day care and respite care. Private insurance policies could provide coverage for additional services (as well as for deductible and coinsurance amounts). Benefits should not be conditional on prior receipt of institutional services.

It is important that any federal long-term care program should include both home care and nursing home services. It is the cost of nursing home services, and not home care services, which the elderly fear. As you know, nursing home costs range from $25,000 to $50,000 per year, and quickly erode both assets and incomes of noninstitutionalized elderly.

To create a long-term care program of home care only would be to repeat the mistakes of catastrophic coverage in which legislation was enacted which did not address what elders perceived as their greatest need. Even home care proponents, such as Robert Ball, acknowledge that:

> "... home care, no matter how desirable, is not going to be feasible for everyone. For example, a very elderly person who lives alone and is becoming progressively incapacitated may simply be better off going to a nursing home, (or to a congregate residential arrangement offering personal care services, in communities where such facilities are available), especially if children and other family members live far away and if high-quality home-care services are not readily avaiable. Trying to design a continuing home-care plan to cover every individual in such circumstances would be futile; the plan would be unlikely to meet their needs satisfactorily and it would almost certainly become prohibitively expensive.

> A nursing home or other congregate setting may also be the best place for people living along who, regardless of age, become so severely disabled that they require full-time care or monitoring. Paying for round-the-clock care at home usually costs more than providing the same kind of care in a congregate setting, and it hardly seems reasonable for the insurance program to pay the extra costs." (Because We're All in This Together, Robert M. Ball, 1989, p. 75).
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> Furthermore, according to Ball,
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> ". . . a public long-term care program focused primarily on paying for home care could not be expected to represent a net saving to the taxpayers, because many people who do not now receive paid for home care at home would be able to avail themselves of such services. But on a case-by-case basis, and especially in situations where paid-for care augments care provided informally by family members, home care, should often prove least costly. . . ." (Ball, p. 13)

To contain program costs, we would suggest substantial deductibles in the form of either dollars or an exclusionary period for both home health and nursing home benefits. Both benefits should be limited in duration, creating an incentive for private insurance to cover the remaining service needs. The home care deductible or exclusionary period should be twice that of the nursing home benefit, because out-of-pocket home care costs are less than half of out-of-pocket expenses for nursing home care. This parity of deductibles would be necessary to ensure that benefits are neutral relative to the site of care.

The home care benefit should also be limited so that expenses cannot exceed 70 percent of the skilled nursing facility rate. Since it is estimated that 30 percent of the cost of nursing home care is attributable to costs for "board," the 70 percent limit will maintain home care and nursing home care on an equal basis. Both benefits should be limited in duration, creating an incentive for private insurance to cover the remaining service needs.

As we discuss the need for services in a continuum of care, it is important that we seek to assure availability of services, regardless of the setting in which the frail elderly individual resides. This may require special efforts to integrate health and supportive services in congregate housing settings. AAHA recommends that the Commission include as part of its agenda an examination of approaches for linking support services with housing as a means of reducing costs for long-term care.

There is an increased likelihood that older persons will rent rather than own homes as they grow older. In addition, their incomes drop, and they are more likely to live alone. Nearly half of all public housing and Section 8 residents are elderly, and the average age of residents at many elderly housing sites has reached the late seventies and early eighties. While these individuals were nearly all independent when they entered the facilities, now about 25 percent of them require some assistance in daily living to remain independent. This "aging-in-place" phenomenon requires a linkage between housing and supportive services, in order to maintain individuals in their community residences. One example of a successful model is the Congregate Housing Services Program (CHSP), administered by the U.S. Department of Housing and Urban Development. That program provides non-medical, in-home services, such as one meal a day, transportation, personal care, and chore services to residents of several federally-assisted projects in an attempt to prevent unnecessary institutionalization and improve the quality of life for frail residents. Much of the success of the program can be attributed to a service coordinator for each project, who helps assess residents' eligibility and arranges access to services. The program reduced the rate of institutionalization of residents almost in half, and saved from $4,000 to $5,000 per person per year, compared to institutional care. Both the Senate and House Banking Committees last year passed legislation that would expand the congregate housing services program in an effort to deal with the long-term care needs of the elderly in subsidized housing. Clearly the need for supportive services to the frail elderly in congregate housing units is a necessary--and cost effective--measure to be included in a long-term care system.

Case management services would be essential to most effectively target services to needs and manage long-term care benefits.

FINANCING

Financing for the federal long-term care program should come from mixed sources of funding.

Lifing the Social Security wage cap has great attraction because that financing mechanism would spread the financial risk for long-term care over a broad base, that is, the working population. Such an approach is appropriate because the very nature of the need for long-term care services in which the risk for one individual is uncertain, lends itself to a solution based on shared risk. Public opinion surveys show widespread public support for using the Social Security wage tax to fund long-term care, even by those individuals who would be paying the higher tax. Those considerations must be weighed against future projections for solvency of the Medicare Trust Fund, however.

Social Security taxes could be augmented by other taxes, such as the surtax on gifts or inheritance transfers. We suggest consideration of a sliding scale on all such income transfers, with no exclusions. Such a tax would expand the revenue base in a progressive and equitable manner. Use of this tax is particularly appropriate given that a major objective of a long-term care program is asset protection.

Use of increased taxes on alcohol and tobacco could also be used to fund long-term care needs.

Additional beneficiary premiums should reflect a beneficiary's fair share of program expenses, without being a burden to those on fixed incomes. In the future, it may be possible to reapportion Medicare premiums to accomplish a more equitable distribution of premiums for acute and chronic care benefits, with some relation to beneficiary income.

At the risk of providing the Commission with its joke of the day, we would urge that any new long-term care system be developed as apolitically as possible. We trust that a major lesson of the Catastrophic Coverage Act experience has been that counting the votes for or against an untested program, which is hyped by some to be what the elderly really wanted and needed, is not enough. We urge a process of presenting options to the elderly and their adult children and providers, as well, and discussing the aspects of financing to determine in advance what will be tolerated. Options should be pre-tested on small segments of the population. We have no illusions that a "quick fix" is in store for financing long-term care. Too many barriers preclude a fast solution to this problem, and those barriers may be even higher, as a result of the backlash of the Catastrophic Coverage Act. While your regional hearings and input from the health and political communities will be helpful to bring options to light, nothing will substitute for testing these options with the groups they are intended to serve.

If the option decided upon by Congress is to resemble an insurance program, and we believe that research suggests an insurance approach may be the most workable, we urge that what is billed as an insurance program actually functions as an insurance program. That brings us to caution you about moving directly to an expansion of the Medicare benefit as it now exists to solve the long-term care financing dilemma.

Frankly, Mr. Chairman, if all third-party payor systems worked the way Medicare works, this country wouldn't have a health care system. No acute care setting would long tolerate an insurance company which keeps providers continually guessing as to coverage and rates, and which places providers at risk for making incorrect guesses. Yet this is what skilled nursing facilities are already expected to accept for participating in the limited Medicare Part A benefit available for long-term care. Hopefully, a comprehensive long-term care program would address some of the shortcomings of the present Medicare coverage payment structure by developing prior authorization for services, and prompt payment for services based on current financial data.

The needs in long-term care are great, and it seems a vast distance from where we are now to where we want to be. While we may disagree on the configuration of a long-term care system, we know we want genuine coverage for our elderly, so old age once more becomes a blessing and not a curse.

Implementation of a long-term care system may be many years in the making, but we have some suggestions for implementing a long-term care program on an incremental basis.

1. Begin with a respite care benefit offered either in the home or in a licensed nursing facility. The benefit should be similar (although slightly more generous) to that under the Catastrophic Coverage Act, but should allow coverage for individuals whose families hire intermittent caregivers to relieve the volunteer caregiver during the three-month exclusionary period. Providing 24-hour care for three months may strain and exhaust the volunteer caregiver so that by the end of that period, institutionalization may seem the most attractive solution. Allowing private payment of some respite care early on may prevent institutionalization;

2. Add a limited adult day health program.

Both of these services would provide support for family caregivers, and if carefully crafted, should be modest beginnings to a long-term care benefit.

3. Add a limited chronic care, home care and nursing facility benefit, with substantial deductibles and coinsurance, as described above.

Mr. Chairman, I appreciate the opportunity to share with you AAHA's views on filling this major gap in our health care system. While implementation of a national long-term care system may be many years in the making, it is important that it begin now. AAHA looks forward to working with you and your Commission as you deliberate on measures to develop a more adequate long-term care policy for our country.

Representative Gradison. Thank you very much, Mr. Goldberg. Ms. Suther?

STATEMENT OF MARY SUTHER, PRESIDENT AND CEO OF THE VISITING NURSES ASSOCIATION OF TEXAS, ON BEHALF OF NATIONAL ASSOCIATION FOR HOME CARE

Ms. Suther. Mr. Chairman and members of the committee. My name is Mary Suther. I'm the CEO and president of the Visiting Nurses Association of Texas, a large voluntary, nonprofit organization serving the elderly and disabled. I've been involved in long-term care provision service in some manner for the last 30 years or more. Also, I am cochair of the Legislative Affairs Committee of the National Association for Home Care.

The national association represents over 6,000 home health agencies and is committed to assuring the availability of humane, high-quality, and cost-effective home care services to those who need them. We appreciate the opportunity to appear before this Commission.

We believe that the foundation of any long-term care program should be home care. Home care improves the quality of life because it is more humane. Home care helps keep families together and maintains the recipient's dignity and independence. It has also proven to be cost effective in providing early intervention and prevention.

In short, we propose implementation of a Federal long-term care program that makes use of the existing infrastructure of the Medicare system, not only of home care, and the Nation's 12,000 home health agencies eligibility should not require that an individual prove indigence, but should be based on need for care.

Benefits should not be limited to the elderly. Many families face destitution because of the cost of caring for their chronically ill children and middle-aged adults at home. Home health services should be the core benefit of this program with services ranging from skilled professional care to personal care including respite care.

It is imperative that the care by the paraprofessional be closely supervised by professionals. Programs should not replace the existing use of family and other informal caregivers, but should provide for access to needed care for all of those without informal support or when that care becomes unnecessarily burdensome for the caregivers.

To administer a long-term care program, it will be necessary to determine whether applicants meet the eligibility requirements and monitor utilization of the benefit. Activities of these kinds are currently referred to as case management. The cost and the potential for conflicts of interest and the long-term nature of the care being decided upon, third parties are reluctant to leave case management entirely in the hands of providers.

On the other hand, there are disadvantages for payers to establish or finance and costly, duplicative effort. It is the payer's responsibility to protect against program abuse and the provider's responsibility to manage patient care. We believe that a balance can be achieved in which the provider remains responsible for case management, and the payer can carry out his utilization management responsibilities without unnecessary conflict and duplicative efforts in patient care planning and review functions.

A prior approval for services after the home health provider has assessed the needs and developed a plan of care, could be utilized as a safeguard. The association supports financing a long-term care program through the use of revenues raised by elimination of the cap on income subject to the 1.45 percent payroll tax. Additional revenue might be obtained by increasing the marginal tax rate on income over $155,000 to 33 percent from the current 28 percent.

We do not believe that private insurance will ever be the only or major factor in financing long-term care. However, it could play an important role in supplementing a public long-term care program and filling gaps in coverage. Medicaid could continue to play its traditional role in supporting of those who have needs not met by Medicaid or private insurance or savings.

Our written testimony includes more detailed information. We appreciate this opportunity to appear before you, and we stand ready to assist in any manner that we might in helping to find a solution for long-term care problems in this country. Like the other panelists, we think there is no one answer.

Representative **GRADISON**. Thank you very much, Ms. Suther. Dr. Evans?

STATEMENT OF LOIS EVANS, D.N.Sc., R.N., ASSISTANT PROFESSOR OF GERONTOLOGICAL-PSYCHIATRIC NURSING PROGRAM, UNIVERSITY OF PENNSYLVANIA, ON BEHALF OF AMERICAN NURSES' ASSOCIATION [ANA]

Dr. **EVANS**. Thank you, Mr. Chairman. I'm Lois Evans, director of the Gero-Psychiatric Nursing Program at the school of nursing, University of Pennsylvania in Philadelphia. I'm pleased today to appear before the Commission representing the American Nurses' Association to address an issue of paramount concern to the ANA, that is, the development of a national long-term health care policy. Nursing is at the core of our current long-term care system, which as everyone knows, is comprised primarily of nursing homes and home health care agencies. Subsequently, long-term care is, by definition, nursing care.

At the hearing held last September 21, this Commission was witness to the personal tragedy suffered by individuals who were unable to obtain appropriate long-term care services for family members. In recent years, it has become painfully evident that these are not isolated cases, but rather all too common examples of a growing trend.

As this Commission begins its deliberations, we understand that much of the emphasis will be on the financing and administration of long-term care services in such a manner as to establish an affordable and effective long-term care benefit. The ANA is aware of the fiscal limitations facing Congress today. We would urge the Commission to incorporate a financing mechanism that is actuarily sound and equitable to the general population and beneficiaries in order to assure the institution of a viable funding mechanism.

For any long-term care strategy to offer the greatest potential for both quality assurance as well as cost containment, the administration of the program itself must be addressed. Our current care delivery system suffers from a fragmentation of both services and providers. To this end, we strongly recommend that the Commission look at the utilization of nursing case management as a means of restraining the fiscal growth associated with long-term care and to ensure a high level of quality services.

Case management is not a new concept, rather it represents the institution of a coordinating mechanism to effectively allocate scarce health care resources to individual beneficiaries in an efficient and timely manner. Several States, communities, and private employers have already utilized case management concepts in the provision of health and social care services. Their experience with the case management concept has provided valuable data demonstrating improvements in the quality health care services, as well as cost savings for payers. As an example, a cancer patient at a local facility here in northern Virginia was prescribed an antineoplastic treatment costing $1,200. A registered nurse, acting as the patient's case manager, contacted several infusion therapy companies for comparative cost estimates. This search found that the cost of the initial prescription was inflated by more than 30 percent above prevailing prices. Both the patient as well as the patient's insurers benefited from the case manager's intervention.

The academic and clinical education registered nurses receive make them uniquely qualified to serve as the primary coordinator of both these health and social care services. Case management entails many elements which create comprehensive care plans. Initial health assessment, the subsequent planning of necessary services, as well as the procurement, delivery, and coordination of these services, are all part of the case management process.

In addition, registered nurses are qualified to both monitor, evaluate, and assess the effectiveness of these services to meet the needs of the client. Such a system promotes quality, ensures efficiency, and most importantly, provides the client contact with a single health care professional to oversee the delivery of their health care services.

The American Nurses' Association's testimony today calls not for an expansion of services, but rather for a new means of administering existing health and social programs to those who are in need of such services. We are firmly committed to providing cost effective, high quality, efficient case management systems.

These would both ensure that beneficiaries receive adequate services to assist them with their activities of daily living, and meet the demands of the policies established by this Commission. Mr. Chairman, a substantial part of the solution to our long-term care problems lies with the largest group of health care professionals in the United States, that is, registered nurses.

We thank you for this opportunity to present our views before the Commission.

[The prepared statement of Dr. Evans follows:]

AMERICAN NURSES' ASSOCIATION
WASHINGTON, D.C.

TESTIMONY

OF

THE AMERICAN NURSES' ASSOCIATION

ON

LONG-TERM CARE: FINANCING AND OPTIONS

BEFORE THE

UNITED STATES BIPARTISAN COMMISSION

ON

COMPREHENSIVE HEALTH CARE

PRESENTED BY
LOUIS EVANS, D.N.Sc., R.N.

OCTOBER 5, 1989

1101 14th STREET, N.W., SUITE 200, WASHINGTON, D.C. 20005 — (202) 789-1800
FAX # (202) 842-4375

Mr. Chairman, members of the Commission, I am Lois Evans, DNSc, RN. I am Assistant Professor and Director of the Geropsychiatric Nursing Section of the School of Nursing at the University of Pennsylvania in Philadelphia. I appear today on behalf of the American Nurses' Association (ANA), the professional association representing the nation's two million registered nurses. I am pleased to present the views of the ANA with regard to the development of proposals designed to establish a national long-term health care policy. Like others, the ANA is pleased with the establishment of the Pepper Commission, and is looking forward to continuing our work with both the members of the Commission and its staff in order to come to grips with the problems facing our national health care delivery system.

The problems facing our national health care delivery system were made painfully clear at the September 21, 1989 hearing before this Commission when witnesses shared with you their personal tragedies which resulted from either an inadequate or nonexistent health care insurance system or a disjointed, meager long-term health care system. As this Commission examines these two shortcomings of our health care policy - the inadequacy of health care insurance and long-term care--it is our sincere hope that the commissioners will consider and adopt many of these proposals presented today. Our comments will focus upon the need to develop a comprehensive long-term health care policy for the chronically ill and others who have ongoing needs, as well as the role of nurses in the delivery of cost-effective, innovative long-term health and social services.

THE PROBLEM

The most conspicuous deficiency in our nation's health care system is the lack of a comprehensive and coordinated long-term care benefit designed to meet the needs of the chronically ill. Ever since the enactment of Medicare, federal policy makers have focused upon the provision of acute health care services. With the enactment of Public Law 100-360, the Catastrophic Protection Act, in July 1988, Congress extended virtually unlimited access to acute care services for Medicare beneficiaries. While ANA and others welcomed this action, we must make note of the fact that long-term care was once again, for the most part, left out of the federal policy debate. The obvious exception was the creation of this Commission and the extension of the skilled nursing facility benefit, which as of this writing, is jeopardized by the attempts to repeal the Act.

Several factors have compelled Congress to consider the development of a national long-term health care policy during this 101st Congress. First, demographic patterns portray our society as an aging nation. As our population ages, health care needs increase. Secondly, the health care needs of the elderly have shifted; most of those who have needs for long-term care suffer from chronic illnesses rather than those which are acute. This has been borne out by several recent studies on the health care status of Americans. Thirdly, the delivery of health care services has changed drastically during the past ten years. Decreased hospital length of stay, advancements in medical technologies which sustain life, and the emphasis on preventive, home, and hospice care all reflect changes in the delivery of health care that we have witnessed over the past ten years. Lastly, health care costs continue to grow at unacceptable rates, far in excess of the rate of growth in the economy in general. In 1965, when

Medicare and Medicaid became law, the nation spent only $41.9 billion on health, equal to 5.9 percent of the Gross National Product. The Health Care Financing Administration (HCFA) projects that spending for existing health programs will exceed $1.5 trillion by the year 2000.

These budgetary trends, in conjunction with the compelling need for the services mentioned at the Commission's last meeting substantiate the need for the development of long-term care policies which incorporate efficient management practices and several cost-saving measures. As these Congressional deliberations begin, several individuals and organizations including ANA, will begin to formulate specific policy proposals to address this issue.

For the most part, our nation's entire health care delivery system focuses upon the financing and provision of acute care services. We do not contest that acute care services are an essential and vital component to any health care delivery system. However, they have been created in part at the expense of the chronically ill. According to some estimates, upwards of eight million Americans need some help with managing the activities of daily living. While we do not contend that it is the role of the government to provide all services to those who need them, the sheer size of this estimated population commands the attention of our policy makers to examine all possible options.

The continued focus on acute care policies reflects the linear development of our federal health care laws, beginning in 1964 with the enactment of Medicare and Medicaid. However noteworthy, this body of law has not undergone a comprehensive review to examine and modify the benefits to meet current needs. Our society's perception that health care is a right of citizenship has successfully compelled politicians to increase their support for the continuation of these programs. However, as exemplified by the establishment of this Commission, it is time to reexamine our health care priorities and initiate necessary policy changes.

POLICY CONSIDERATIONS

Cost. In addition to the institutional hesitance to develop a comprehensive long-term health care plan, we are cognizant of the fact that health care policy in our nation today is a matter of budget policy. It is estimated that our nation currently spends twelve percent of its gross national product on health care services. Total expenditures equal $244.3 billion, which represents a $1,721 per capita expenditure (1985 data). Of these amounts, $35.2 billion accounted for nursing home care. Clearly, this represents a staggering investment in our health care delivery system. More importantly, however, is the fact that this seemingly endless drain on our national budget has compelled lawmakers to look at proposals which increase our level of federal spending on health care services with a skeptical eye. Few can argue successfully with the fact that we are currently working within an economic atmosphere that forces legislators to operate with fiscal restraint. Therefore, it becomes incumbent upon policy makers to look at reordering our health care priorities, rather than developing new services or delivery models which would further exacerbate our federal deficit. The ANA believes that the recognition of fiscal limitations by policy makers must be addressed in order to develop a workable, acceptable solution to the deficiencies in our health care delivery system.

Administration. Central to the deliberations of this Commission will be how to administer any new or expanded long-term care benefit. Currently, Medicaid, the jointly funded, federal/state program that provides institutional care for the chronically ill elderly, is the only national program that offers long-term care to eligible beneficiaries. However, Medicaid benefits are only made available after the individual beneficiary impoverishes himself to meet eligibility criteria. Such an onerous requirement reflects the enormous deficiencies in our long-term health care policies, which in effect erects the ultimate barrier to care.

Financing. In developing any health care delivery system, the mechanism of financing is of paramount importance. Because the cost of providing long-term care is expected to be high, it is incumbent upon policymakers to examine various financing alternatives and to explore innovative methods of cost-spreading that involve the private as well as the public sector. Any financing scheme for long-term health care must not only be actuarily sound, but also equitable to the general population and to beneficiaries.

Scope. An effective long-term health care policy must define what services will be included to serve beneficiaries' needs, how such services may be delivered, and by whom. The phrase "long-term care" embraces a wide array of medical, nursing, social, personal, and supportive services that are required by individuals who have lost some capacity for self-care. Emphasis should be placed on efficiency in the delivery of services utilizing innovative concepts, such as the de-institutionalization of individuals who, with the proper management of their health and social needs, could continue to reside in their communities. The coordination of these health and social services could be provided by nursing case managers to meet the needs of these individuals.

There are many other factors that must be considered in developing a comprehensive effective, and efficient long-term health care policy. Such policy considerations should focus on providing the most flexible program possible, while ensuring the highest quality and widest range of services for those in need of long-term care.

CURRENT ROLE OF NURSING IN LONG-TERM CARE

Nursing's role in the provision of long-term care has traditionally been stron The vast majority of long-term care services are provided in our nation's nursing homes. Naturally, these facilities are staffed almost exclusively by registered nurses and para-professional nursing personnel. Current Medicare law for skilled nursing facilities only requires that a physician visit a resident once every sixty days, after the first ninety days of residency. Medicaid law, which applies to the majority of nursing home residents, requires that the resident's physician see the resident every ninety days. The timetables established by these laws acknowledge the limited role the physician plays in the day-to-day provision of long-term care services, and supports the contention that, for the most part, long-term care is nursing care.

Another primary component of our current long-term care delivery system is home health and hospice care. Here too, nurses are often the primary care giver and also serve to a great extent as the coordinator of care. Medicare requires that home health agencies be managed by either a physician or a licensed, registered nurse. Again, this recognition of the value of the professional nurse in this setting compels the utilization of this cadre of health care professionals in both the provision and management of these services.

Finally, nurses often function as case managers in the delivery of long-term health care. Long-term care, regardless of the setting in which it is provided, represents a range of services that address the health, social and personal care needs of individuals who, for one reason or another, have never developed or have lost some capacity for self-care. By definition, this population is best served by professional nurses who, by virtue of both their academic as well as clinical education are best prepared to address the multitude of needs of this particular patient population. Nurse case managers not only focus upon health maintenance, disease prevention, and health promotion. but also upon coordinating care with other professional members of the health care team.

Often, the coordination aspects of the nurse case manager can result in more cost-effective care.

A recent example of which we know reflects this. A cancer patient at a local facility was prescribed an antineoplastic treatment costing $1,200. The nurse case manager, believing this cost to be inflated, called several pharmaceutical companies for estimates on the cost of the treatment. The original drug company, finding out about the nurse case manager's actions, reduced the cost of the treatment by 57%.

While the utilization of nurses as case managers is by no means novel, it is a concept that has only just begun to enjoy implementation in the long-term care setting.

POLICY RECOMMENDATIONS

The ANA offers the following recommendation's to the Commission in its quest to develop a policy on long-term health care:

1. Establish and adopt a multi-level, long-term care system that recognizes the varying levels of needs of the chronically ill a provides for a continuation of care.

The medical focus of our current health care policies generally reflects an episodic approach to health care delivery rather than a system designed to follow a continuum. Such an approach is best suited to the provision of acute care rather than long-term care services. Nursing, throughout its history has promoted the philosophy of continuity of care. This reflects a belief that all health care services should be comprehensive, rather than episodic.

ANA believes that the lack of comprehensiveness and continuity, in addition to the fragmentation of services currently being provided to long-term care beneficiaries, must be corrected by instituting a coordinating mechanism which meets both the health care and social needs of its clients. The institutionalization of such a mechanism would both improve access to and increase the quality of covered services.

2. Incorporate a mechanism in the long-term health care policy which utilizes registered nurses as primary coordinators of a case management system.

The case management system has proven to be a useful means with which to effectively allocate scarce resources in an efficient manner. Many elements comprise the case management system. Health assessment; the subsequent planning of services; the procurement, delivery, and coordination of services; and finally, the monitoring of the effectiveness of these services to meet the needs of the beneficiary are all combined to efficiently address and provide all of the services necessary to assure a high level of care to the client along a continuum.

The implementation of a comprehensive case management system would not be a new approach to service delivery. In the 1971 Social Security Amendments Section 1115 provided for home and community-based waivers that allowed States to provide federally-mandated Medicaid services on an outpatient basis. This trend continued for Medicare programs under provisions of Section 222 of the 1972 Social Security Act Amendments. The federal government continued to demonstrate their support for this trend with the establishment of 13 community-based long-term care demonstration sites called, "channeling projects" in 1980. Individual states and municipalities have demonstrated their support for the case management concept with the establishment of the Georgia Alternative Health Services Program, the Wisconsin Coordinated Care for the Elderly program, the Washington Community-Based Care for the Functionally Disabled, the New York Long-Term Home Health Care program, and the On Look Community Care for Dependent Adults program in San Francisco, California.

Interestingly, the stricter budgetary limitations imposed upon individual states have compelled their further interest in providing managed care. Deficit spending is not an option for most State Governors. Subsequently, the individual States are forced to identify the most cost-effective means necessary to provide federally and state-mandated services to their beneficiaries. Case management has proven, for them, to meet this important objective.

In summary, the incorporation of professional nurses in the care and management of long-term care will promote the most efficient utilization of the nation's largest group of heath care providers.

3. Provide eligibility criteria which allow patients options or alternatives to institutional care.

The historical development of ANA's long-term care agenda has focused upon shifting from institutional long-term care to home and community-based long-term care services. The ANA has endorsed legislative proposals that would offer providers, beneficiaries and insurers options to institutional health care delivery. In general, the ANA supports the creation of a multiple-level, long-term health care delivery system which would offer beneficiaries access to a broad and appropriate range of services, either in their homes, a walk-in clinic, a community facility, or within an institution. The key to the successful application of the vast array of health care services associated with any such delivery system is that the beneficiary receive all necessary services in the most cost-effective and least restrictive setting as possible.

We also urge the incorporation of provisions to ensure universal access for all Americans who are in need of these services which will enable them to be eligible for these programs regardless of the individual's ability to pay. Eligibility for beneficiaries should be based upon functional disability rather than specific illness. Further, ANA believes that the mental health needs of clients should be addressed and served as well as their physical impairments.

While it is true that the Medicare program offers some home health care benefits, the qualification criteria established for these benefits, as well as budgetary limitations on this program, prevent it from being inclusive and long-term in nature. In fact, the eligibility criteria for any long-term care benefit must be reviewed in order to assure that access to the proposed service relates to the actual need. Currently, eligibility is determined by a physician who makes determinations in conjunction with statutory limitations defined in law. Such subjective evaluation criteria rely upon evaluations made by physicians, usually in conjunction with a medical diagnosis. Because chronic ailments do not necessarily involve medical problems, the development of other eligibility criteria is necessary.

4. Include input from nursing in the oversight of the long-term care policy that is adopted.

The ANA, like many of the Commission's members, has noted with great dismay, that the Department of Health and Human Services' Social Security Advisory Council, which in part is to examine the long-term care needs of the chronically ill, chose not to include professional nursing in its membership. This is not an isolated occurrence. All too often it is the norm. We raise this point to demonstrate that nursing and nursing care appears to be taken for granted or is undervalued by policy makers. This perceived devaluation of nursing services is fostered by our Medicaid program which forces recipients to impoverish themselves in order to become eligible for institutional long-term care benefits, and that nursing care in general is inherently worth less than acute care services. The majority of long-term care in this nation is provided by nurses. Therefore, it is essential to include the viewpoints and expertise of the professional nursing community in substantive decision-making which relates to long-term care.

5. Adopt a financing mechanism for long-term care which is equitable to the general population and to beneficiaries.

The American Nurses' Association urges this Commission to recognize and accept the limitations imposed either directly or indirectly upon our legislators today. Of paramount concern is the potential impact the development of any long-term care policy may have upon the federal deficit. ANA does not advocate an expansion in health care benefits without provisions for adequate financing. Such financing could arise from a reordering of existing priorities for the funding of federal programs or through increased revenues. The options available for the latter are numerous, and could be achieved, we believe, with a minimum impact. Protection for the low and moderate income beneficiary must be included in the structure of co-payments, deductibles, and premiums associated with the programs proposed. Whatever financing this Commission ultimately recommends, we strongly believe that it must be adequate to minimize the financial impact upon the individual.

SUMMARY

The American Nurses' Association's testimony today calls not for an expansion of services, but rather for a new means of administering existing health and social programs to those who are in need of such services. The ANA is firmly committed to the concept of implementing nursing case management programs that would provide a cost-effective, high quality, efficient means of ensuring that beneficiaries would receive adequate services to assist them with their activities of daily living, and meet the demands of the policies established by this Commission. Mr. Chairman, a substantial part of the solutions to our long-term care problems lies with the largest group of health care professionals in the United States - registered nurses. We thank you for this opportunity to present our views before the Commission.

Representative GRADISON. Thank you, Dr. Evans. Are there questions? Dr. Davis?

Commissioner DAVIS. Thank you, Mr. Chairman. I would like to ask Dr. Willging a question, if I may. I'm intrigued and agree with your idea that in the current climate, we must look longingly at Medicaid and how that can be improved as one, if not the, major vehicle of providing care.

I was intrigued by your commission on Medicaid and wonder if you would elaborate a little bit on this, how it would be set up, and in your mind, some of the recommended changes in current Medicaid provisions that might be considered.

Dr. WILLGING. I'd be happy to briefly do that, doctor. The independent commission, in my mind, is a mechanism whereby for the first time, State reimbursement methodologies—and remember Medicaid is the primary funding source for long-term care—would be forced to undergo a scrutiny which makes such that the rates established are in accord with the requirements for high quality care that we wish nursing homes to provide.

It would have to be extremely independent but at the same time bring to bear the general expertise of both consumer advocacy groups, provider groups, Government, businessmen, and the like. I think that is one way of, for the first time in the history of the Medicaid Program, making sure that both the requirements for quality care and the resources available are somehow synchronous rather than disparate as they are today.

I think at the same time, we want to begin to look seriously at whether there should be greater standardization in terms of eligibility under Medicaid because Medicaid—forget long-term care for the time being—covers only about 60 percent of those who are poor in this country.

I think that Congress is already doing some of that in the sense of some recently passed legislation on spousal impoverishment and other such activities. In a nutshell, I believe if we are going to have to, fortunately or unfortunately, rely on Medicaid as the primary public funding source, let us at least make sure that it fulfills a bare minimum the promise that it could bring to the American people.

Commissioner DAVIS. Help me a little bit on who would bring this independent commission together?

Dr. WILLGING. It would need to be enacted through legislation by the Congress. That could be done fairly easily. It is essentially a low-cost proposition, but would for the first time, begin to bring some consistency in terms of reimbursement approaches, not in the sense of setting rates for Medicaid Programs, but assuring that the rates set by the State are in accord with the regulatory requirements and the needs of the patients, but it would require an act of Congress.

Commissioner DAVIS. Independent of Congress, not reportable to Congress?

Dr. WILLGING. It would be independent in the sense that it would not report to the executive branch and would not report to State government or to the Congress in the sense of the direction, but certainly report to the Congress in the sense of reporting on its activities on an annual basis.

Commissioner DAVIS. But not really strictly accountable to Congress?

Dr. WILLGING. It would be accountable, essentially, to the patients in long-term care facilities across the country.

Commissioner DAVIS. Mr. Chairman, just briefly, I'd like to commend Mr. Goldberg on his plan for bringing a private-public cooperative system together. I think your testimony will help us a great deal. I commend you on your thoughts and words on this.

Commissioner BALOG. Mr. Chairman, a question please. I'd like to address my question to Dr. Evans and perhaps to anybody else that wants to comment on it. In your remarks, you talked about the focus of our present system being on acute care. I've long had that same view that what we now have is a misnomer, Medicare. It's a Medicure system.

I was wondering if you've given any thought to how we might rebalance the resources being put into the Medicure system to have some for the Medicare system, such as perhaps more copays on the present Medicure hospital stays, or any other ideas you may have on how to rebalance where our resources are now going?

It seems to me that when the older folks first get ill and they need acute care, there is a fairly good support system. When they get older, it is a drop off a cliff. There is nothing there. Can we rebalance the resources?

Dr. EVANS. I can speak to it from the perspective of the care that is required and some of the initiatives that are being taken to try to facilitate that care.

What we need to address is the fact that acute care is really increasingly, part of the long-term care system. We have tended to think of it as a very separate system. What we're finding is that people with chronic illnesses become acutely ill, enter the hospital and then have increasing care needs on their discharge. One of the things that we're researching at the University of Pennsylvania is the effectiveness of a case management system in the hospital in ensuring that patients get what they need when they leave the hospital on a timely basis so that their care is coordinated. In the early pilot work, we have data that documents a decreased cost of care for those patients when the nurse case management system is in place. This is an example of how we can begin to move the expenditure of dollars out of the acute care setting; some mechanism needs to be in place for allowing continued care at a much less expensive level in the home or in community-based settings.

In terms of a policy for how we ought to change the proportions of moneys that are going into these different programs, the American Nurses' Association is currently considering a relevant policy recommendation. We'd be glad to submit that to you at a later date.

Dr. WILLGING. If I could, Mr. Balog, from the perspective of nursing and, although I'm not a nurse, I'd like to point out that three of my sisters are, which gives me the authority to speak on that issue.

I think that nursing does make your point that our health care system has short-changed long-term care at the expense of acute care. I'll throw out just one statistic to make that point.

It is not generally known, but it is indisputably true, as indicated in the Secretary's Commission on Nursing last year, that in nursing homes, for example, a nurse is paid 65 percent of what that same individual is paid in a hospital. Again, not because of caprices by nursing home operators or administrators, because the nature of our financing and funding systems, dependent largely on Medicaid, force arbitrary constraints on our ability to provide the kind of care we would like.

And I agree with Dr. Evans—long-term care is a service modality which relies almost exclusively on nursing. Unless we begin to sort out these problems with the financing system, we will always short-change long-term care.

If I could add one point to that. We need a continuum of care. Hospitals are part of that continuum of care. It is an important and interesting fact that over 50 percent of revenues going to American hospitals are for persons over the age of 65.

Dr. EVANS. If we could also point out that the highest amount of money that is being paid out for Medicare is really in the end stages of life when patients are in the acute care setting. Many of those folks, if they had another option, would prefer to end their life in a more humane setting; for example, a skilled nursing facility or at home with appropriate supportive services from nursing and other personnel. I would think that we could cut savings a great deal as well as improve the quality of life for those patients and their families if we would look at other ways of supporting this kind of care.

Ms. SUTHER. I would like to address that issue, too. I think that a step in the correct direction would be to look at Medicare in its place. One of the problems that we have is every time we affect one benefit, we affect another. We take away from one and add to another. If you look at Medicare in the context of the entire provision of public services and private services, some States have varying Medicaid benefits.

If a patient is not allowed to have drugs when they go home, then they end up in the hospital again, or they can't be maintained in the home if they can't be supported by the Medicaid system in the home and, therefore, they go back into an acute care facility. We need to look at what happens to one part of the continuum of care when we mess with the other part.

Representative GRADISON. Mr. Chairman, as I hand the gavel back to you, figuratively, I want to explain to the Commission that the splendid irony is that I'm going to have to leave this hearing on long-term care in a few minutes to go to the floor of the House to vote on child care legislation.

Thank you, Mr. Chairman.

Chairman ROCKEFELLER. If there are no more questions, I thank the panel very much and apologize for my absence. We can now go on to the next panel, which will be Dr. Paul Willging of the American Health Care Association——

Dr. WILLGING. We just went. I'd be happy to do it over again, Mr. Chairman.

Chairman ROCKEFELLER. I thought that I should have the right to hear this all over again. I apologize to everybody. I hope nobody can see my blush.

Richard Schweiker, president of the American Council of Life Insurance; Carl Schramm, president of the Health Insurance Association of America; Gail Shearer, manager, public policy, Consumer's Union. We welcome you and will give you a chance to have a seat. Richard Schweiker—it is good to see you back and will start with you if you're ready.

Mr. SCHWEIKER. I appreciate that very much. I wonder if I could just yield and let my colleague, Dr. Schramm, go first.

Chairman ROCKEFELLER. All right.

STATEMENT OF DR. CARL SCHRAMM, PRESIDENT, HEALTH INSURANCE ASSOCIATION OF AMERICA

Dr. SCHRAMM. Thank you, Mr. Schweiker. Mr. Chairman, members of the Commission—Dick and I have attempted to coordinate our testimony today. I'm going forward with some more generic comments on long-term care from the private insurance perspective. Dick is going to talk a bit more about specifics with regard to tax policy and other financing arrangements.

We appreciate the opportunity to talk to you today about the role of the Nation's private insurance industry and the whole question of long-term care. Over 100 companies provide long-term care insurance protection and products to over 1.3 million people. That may not sound like a lot of people at first, but 4 years ago, there were only a handful of companies, about 10 or 12 offering a small number of products to virtually no one.

That represents part of the problem we're dealing with; namely, an acute change in the level of information and awareness of the problem. I begin today by summarizing my submitted testimony with four points. First, we suggest that the current financing system is unacceptable. It is not a system at all. Financing of long-term care is very complicated as all the witnesses have pointed out this morning.

Thus, we would counsel that as we proceed forward, we have to do it carefully, with a sense of what the public's responsibility is and what the potential for private participation and the force of the private market is.

The second point I make is that fiscal realities essentially force us into this position. As you well know, we currently spend about $56 billion on long-term care with approximately $30 billion being spent by the public. We cannot move to a system of full funding with either the public side or the private sector taking the full burden. That is just a pragmatic reality it seems to us.

Third, there is a growing and critical role for private insurance to provide a better means of financing long-term care. I think, as history bears out, the potential here is very great.

Finally, there continues to be a critical role for Government, independent of financing care, in trying to understand and improve our knowledge of what is absolutely necessary. Our knowledge base as regards to the elderly, certainly around the question of their long-term care needs, is in its infancy and Government must take the leading role in improving this situation.

We would offer six points to consider specifically for action. First, we must begin a program to educate the public. As I pointed out, the relative burgeoning of the private market really relates to the sense that only in the last 3 or 4 years has it emerged in America on the consciousness of elderly people that Medicare itself does not provide long-term care benefits.

I think the pressure that the Congress feels, pressure that apparently is making a viable and active market for us, really emerges from a growing sense among the elderly of their exposure of their risk and of their responsibilities and of Government's responsibilities to move forward to offer a system of protection.

The second point is that we must improve Government's ability to target assistance to those most in need. The Government must take the full responsibility for providing care to those without the resources to care for themselves or to buy protection against the risks that we now understand more clearly.

Third, we must stimulate the private insurance market through clarifications of the Tax Code which Dick is going to speak to in a great deal more detail than I am.

The fourth point we would make is that we must see State regulation of private long-term care insurance. Consumers must have access to products with solid protection. The passage of the NAIC [National Association of Insurance Commissioners] model bill in the remaining 13 States without such standards, is of paramount importance to the Nation and certainly to this association, which has worked with NAIC in developing those standards. These are consumer protection standards that are vital to protect the interest of consumers by insuring the highest quality products.

The fifth point is that we must continue Government's support of long-term care data collection and research. All of society benefits from the activities that are now underway, such as biomedical research investigating the causes of chronic illness and national surveys of the demographics of the elderly population.

Finally, we would suggest the promotion of cooperative public and private financing and delivery experiments and arrangements that are currently underway. We are concerned that just yesterday legislation allowing State demonstrations of public and private long-term care insurance partnerships pending in the Finance Committee was changed rather radically.

We would hope that the committee would consider the restoration of all 10 demonstration project sites cooperating with the Robert Wood Johnson Foundation.

Mr. Chairman, that summarizes my remarks and I thank you.

[The prepared statement of Dr. Schramm follows:]

Statement
# of the
Health Insurance Association of America

on

PRIVATE LONG-TERM CARE INSURANCE

Presented by
Carl J. Schramm
President

Before the
Pepper Commission

October 5, 1989

Good morning Mr. Chairman and Members of the Commission. I am Carl J. Schramm, President of the Health Insurance Association of America (HIAA). HIAA represents some 350 insurance companies which write over 85 percent of all commercial health insurance in this country.

We appreciate the opportunity to talk to you today about our role in helping to pay the nation's long-term care bill. Let me begin by summarizing the most important points of my testimony.

- The current financing "system" is unacceptable. The financing of long-term care is complicated and requires a thoughtful solution, not a rush to judgement.
- Fiscal realities and other national priorities make it irresponsible to place the financing burden primarily on the federal government. All elements of society -- individuals, families, volunteer organizations, employers, and insurers must also play a vital role.
- There is a growing and critical role for private insurance to provide a better means of financing long-term care for those who can afford to protect themselves.
- There continues to be a critical government role, independent of financing care, in furthering our collective knowledge about who needs long-term care, what services should be provided, and what the total costs to society will be.

The HIAA long-term care financing proposal has the following objectives:

1. Educate the public. Without understanding the problem, the public cannot be expected to understand the appropriate solutions.
2. Improve the government's ability to target assistance to those most in need. The government must take full responsibility for

providing care to those without resources to care for themselves.

3. Stimulate the private insurance market through clarifications and changes to the tax code. Such actions offer immediate help for today's elderly. And, they offer a longer range solution for tomorrow's elderly who have the time to prefund for their potential long-term care needs on an affordable basis.

4. Encourage state adoption of the model long-term care insurance bill developed by the National Association of Insurance Commissioners. This bill protects consumers and permits needed flexibility for a developing line of insurance.

5. Continue government support for long-term care data collection and research. All of society benefits from activities such as biomedical research investigating the causes of chronic illness and national surveys of the long-term care population.

6. Promote cooperative public-private financing and delivery arrangements on an experimental basis. A comprehensive national policy should be based on a full understanding of the alternatives and their cost-effectiveness.

The public and private sectors must take time to make the necessary investments in designing a financing arrangement that we can live with today and our children can live with tomorrow.

Nature of the Problem

When we speak of "long-term care," we are describing a wide range of health and personal care services provided to individuals who have lost some or all capacity to function independently due to a chronic illness or condition. According to AARP, an estimated 9 million elderly will have long-term care needs by the year 2000. About 70 percent of the noninstitutionalized elderly with long-term care needs receive all their help from family members and friends. However, 30 percent receive additional paid home care services and about 40 percent of all elderly will spend time in a nursing home.

Long-term care is the major catastrophic health care expense faced by the elderly today. For those elderly who have out-of-pocket health care expenses over $2,000 a year, an average of 80 percent is spent on nursing home care. With nursing home costs estimated to average $25,000 a year, such expenses can indeed cause financial ruin.

The current system for financing long-term care is clearly unacceptable. Instead of pooling risks, it places each household on its own and Medicaid becomes the payor of last resort when household resources are depleted. This system, combining out-of-pocket outlays and welfare, features remediation and relief when prevention and planning would be preferable.

Moreover, the long-term care problem is not just a financing one. Long-term care delivery systems are fragmented and piecemeal; case management models to coordinate and manage costs are still being developed and refined, and there is no guarantee that one model will be appropriate for all communities. The most efficient payment methods for providers are still being tested and evaluated. Data on long-term care service use are inadequate for fully understanding the current situation or for making accurate estimates about future utilization and costs, especially for community-based services.

These significant unknowns should make it clear to both the public and private sectors that more than a funding solution is required. The situation calls for innovation and experimentation on a manageable scale, not a quick plunge into a national "solution" that fails to recognize how these financing and delivery issues affect costs and access to care.

Appropriate Public Financing Role

An estimated $56 billion was spent on all long-term care services in 1987. Over half, $30.6 billion, was paid by the public sector. Assuming no change in our current financing system, the Congressional Budget Office has estimated that this figure could increase between 50 and 200 percent by the year 2000.

Given today's fiscal realities and competing national priorities, we cannot expect the public sector to continue to take on such an enormous and unwieldy financial responsibility. Instead, HIAA believes that public policy should be targeted toward finding ways to more effectively use the private resources already being spent for this care, thereby reducing future public long term care expenditures. Those who can afford to protect themselves should be encouraged to do so.

It is not the role of government to protect and preserve assets or income levels of individual citizens against the various contingencies of life. In general, it is the responsibility of individuals to plan for their own needs to the maximum extent possible. It is the role of government to provide sensitive and responsive support to those who face needs beyond their individual financial capacity to deal with them.

The government should target its limited resources to assist those who can least afford such protection. Private insurance products are not designed for, nor do they lend themselves, as financing vehicles for people who are already quite old, disabled, or poor. Providing care for this population should be the objective of the public sector, and reforms are needed to improve the government's ability to act as a responsible safety net for those who must rely on it.

New Developments in Long-Term Care Insurance

Paying for long-term care is a significant financial obligation we face today and will only become more urgent over the next forty years as the population continues to age. The nature of long-term care is such that, given the opportunity and knowledge, the vast majority of Americans would prefer to make provision for their own economic needs and support services through appropriate savings and risk management vehicles.

A national survey conducted last year by the University of Maryland's Center on Aging found surprising willingness by the public to purchase a long-term care plan if it met their long-term nursing home and home health care needs. Overall, over one-half of those surveyed indicated they would pay $100 a month for such a plan. In addition, two-thirds of full time workers said they would be more willing to purchase a policy if it were offered by their employer, even if the employee paid all or some of the premium.

By thoughtful, competitive and broad-based expansion of private insurance, the proportion of long-term care financed by the private sector will gradually increase and will be distributed among individuals in a more manageable fashion than it is today.

The long-term care insurance market is developing rapidly, as evidenced by the number of companies developing products, the number of individuals covered and the variety of products being developed. There are now over 100 companies selling a long-term care product and almost all of this growth is since 1985. Today, about 1.3 million persons have purchased a long-term care plan.

More importantly, the products themselves are changing. The earlier products tended to be more limited. For instance, they covered only stays in a nursing home and then only following a hospital stay. But virtually all the newer products offer coverage of nursing home and home health care, without institutional gatekeeping mechanisms like prior hospitalizations. Instead, benefits are often triggered based on the need for assistance in personal care functions such as bathing, walking, and dressing. In addition, they provide inflation protection against future long-term care costs. We will see a continued trend toward more comprehensive and liberal benefit provisions as the market place becomes more competitive.

The recent introduction of employer-sponsored plans is particularly promising. These employee pay-all plans offer the opportunity to reach a large number of people efficiently during their working years when premiums are more affordable. Coverage in the workplace offers the additional advantage of employers selecting the best plan at the best price for their employees.

Since 1987, over 35 employers have offered such coverage. Two-thirds of this growth occurred this year and we can expect several more plans to be offered within the coming year. Enrollment experience from 1988 employer group plans shows the average age of employees electing this coverage is about 40. This is strong evidence that with education, younger people can and will purchase long-term care protection. And, most of these plans offer coverage to the elderly as well by including retired employees and their spouses and parents of the employee and employee's spouse.

Challenges to the Long-Term Care Insurance Market

HIAA believes that several factors could hasten the development of private long-term care insurance and strengthen its ability to respond to the public's demand and need for long-term care protection.

Educating the Public

The need for better consumer education is the responsibility of both the private and public sectors. It is virtually impossible to sell a product to someone who already believes they have it.

However, this is where we find ourselves with long-term care insurance. Education should begin early, so that working age people can plan for their potential long-term care needs while they have the income to do so.

HIAA has undertaken a number of initiatives in this area. One example is the "Consumer's Guide to Long-Term Care Insurance". Over one million copies have been distributed. After an ad campaign last fall, we received over 1500 consumer requests a week. The government run Consumer Information Center in Pueblo, Colorado has received requests for several thousand copies. It is clear the public wants information on this subject. HIAA remains willing to work with all levels of government to further similar communication and education efforts.

Information and Research Needs

The development of an effective long-term care insurance policy and its appropriate pricing relies on a good body of data. Although insurers are gaining more experience in long-term care, the federal government remains the most effective organization for collecting and analyzing data on a large scale basis. Surveys such as the National Long-Term Care and National Nursing Home Surveys provide invaluable information to public and private decision makers alike. The federal government must continue this important function by providing data in a useful and timely manner.

In addition, more government resources are needed in basic and applied biomedical aging research to facilitate the management of chronic disease and disability. Treatments which ameliorate or control conditions such as Alzheimer's disease, incontinence, and osteoporosis will greatly enhance the quality of an older person's life and significantly reduce the need for costly long-term services.

Lastly, many needs of chronically disabled individuals, such as running errands, doing odd jobs around the house, and enjoying social visits, cannot be expected from a publicly or privately financed program. Our voluntary service sector must mobilize to more systematically meet the needs of a society that will continue to age. The public sector could play a vital role in stimulating these actions.

Combining our collective knowledge, the public and private sectors can move toward the design of the optimal long-term care program. Better utilization data are needed. Better strategies for delivering appropriate but cost-effective care must be developed. Better methods for assuring high quality providers through greater numbers of well-trained personnel are needed. And, more basic and applied biomedical research is essential to help identify ways of reducing the need for long-term care services. To this end, HIAA supports research and demonstration efforts such as the Robert Wood Johnson Foundation planning grants to the states to develop public-private financing and delivery models for long-term care.

Federal Tax Environment

Long-term care insurance is a new product with an uncertain status under the federal tax code. In order to stimulate the growth of private insurance, especially employer sponsored coverage, and reduce its costs, the federal government needs to clarify its tax status. Such actions include:

- giving long-term care insurance the same tax status as health insurance with regard to the treatment of premiums paid and benefits received under individual and group contracts,
- promoting employer sponsorship of long-term care insurance as an employee benefit by removing restrictions that inhibit prefunding of retiree benefits and be permitting long-term care insurance as a cafeteria plan benefit, and
- permitting a variety of existing asset accumulation vehicles, such as pension plans and life insurance, to be modified to include long-term care options.

In addition, some form of limited premium subsidy for the purchase of long-term care insurance might be considered. This approach could be especially beneficial for today's elderly who did not have the opportunity to buy private insurance at a younger age when premiums would have been more affordable.

All of the above recommendations have been supported by the Congressionally mandated Task Force on Long-Term Health Care Policies and former Secretary Bowen's report on catastrophic illness. We believe that these incremental actions are affordable and would contribute to the ultimate development of a public-private partnership.

State Regulatory Environment

Long-term care insurance is a new product that continues to evolve. Insurers need a state regulatory environment which is sufficiently flexible to allow for the development of new and different products but is equally effective in protecting consumers. In December 1986, the National Association of Insurance Commissioners (NAIC) first adopted model legislation that successfully balances these two objectives. The model statute has been modified several times since then to better meet consumer need. As of July, 26 states had passed legislation based on the model bill and another eleven had passed legislation or adopted legislation more stringent than the model.

We are encouraged at the speed with which states have acted to govern this new product. As an industry, we must minimize the potential for consumer abuses if we are to sustain a viable market. It is a top priority of this Association to work actively in those remaining thirteen states for its passage.

Summary and Conclusion

We all agree that solving the nation's long-term care problem is vitally important. HIAA believes that the flexibility of private insurance offers families and the elderly the preferred approach to prefunding long-term care for many Americans. And, over time, we believe private insurance will give millions of people an opportunity to be financially independent throughout their retirement years.

Given this promising start, government budgetary pressures, and many important health care priorities, HIAA believes it would be a mistake to minimize the role of private insurance in designing a comprehensive national policy for long-term care. Instead, the public and private sectors must combine their efforts and knowledge to create a solution that will benefit most Americans today and in the future. This investment will pay off many times over as you and I grow older and it will help us avoid placing an insupportable tax burden on our children.

As HIAA moves forward in developing our financing proposal in more detail, we would be pleased to meet with staff and members of the Commission for further discussions.

Thank you Mr. Chairman and Members of the Commission. We look forward to working with you to provide further assistance in this area.

Chairman ROCKEFELLER. Thank you, Carl, very much. Mr. Schweiker?

STATEMENT OF RICHARD S. SCHWEIKER, PRESIDENT, AMERICAN COUNCIL OF LIFE INSURANCE

Mr. SCHWEIKER. Mr. Chairman and members of the Commission, I am pleased to testify today on behalf of the American Council of Life Insurance about the efforts of the life and health insurance industry to address the overwhelming costs of long-term care for our elderly citizens.

There is currently no program, either public or private, which provides protection to most people against the devastating financial impact these costs can have on the elderly. The current tax laws put serious impediments in our way. My message today is to urge modifications in these laws that will create an environment in which employers and individuals will be encouraged to purchase protection against the huge cost of long-term care.

The most important change would be to treat long-term care benefits paid under life and health insurance policies like health insurance benefits. My prepared statement sets forth the details of all the tax changes we believe are necessary.

The life and health insurance business is ready and able to provide innovative and cost-effective insurance arrangements to provide such protection. The number of companies developing long-term care insurance products and the variety of products being developed, has been increasing.

Today, more than 100 life and health insurance companies are offering long-term care insurance protection. The extent of coverage is, however, quite small, relative to the potential. Moreover, we expect coverage will remain small unless needed changes are made in the Tax Code.

Let me briefly outline several innovative developments which I think will clearly indicate the potential for broad-scale, long-term care protection through the private sector.

Initially, long-term care policies were sold only to individuals, but now long-term care protection is also being offered through employer-sponsored group programs. The tax law should be clarified to encourage this development since employer programs will greatly accelerate the expansion of long-term care protection.

Another important development is that life insurance companies are designing riders that can be attached to a life insurance policy under which a portion of the death benefit will be paid early to meet long-term care costs. This can be an extremely cost-effective approach to long-term care protection. Moreover, since the riders can be added to existing policies, they provide an opportunity for instant broad-scale coverage.

In a recent survey commissioned by the council, almost 60 percent of those individuals who already owned life insurance indicated that they likely would have purchased such riders had they been available when they purchased their policies.

In addition, almost 40 percent of those who do not currently own life insurance, indicated that they might purchase life insurance if it included a long-term care rider. Now, to demonstrate this huge potential, 103 million people own life insurance today, with a face value of $4.5 trillion.

In 1988 alone, $1 trillion of life insurance was purchased. As you can see, we're ready to accept the challenge, but we need tax law clarifications and changes to encourage individuals and their employers to respond.

Mr. Chairman, in some of our discussions with the Internal Revenue Service and others, the issue has been raised as to whether the inclusion of cash values or similar nonforfeiture values in long-term care policies should adversely affect the tax treatment of these policies. We think not. Let me briefly explain.

Nonforfeiture values are common in life insurance policies when premiums are paid in a level amount each year or under some other schedule which avoids sharply increasing premiums at older ages when insurance costs are highest. For the same equity and consumer reasons, nonforfeiture values are clearly appropriate in long-term care policies.

In summary, Mr. Chairman, the potential devastating costs of long-term care is a critical issue for the elderly and needs to be addressed. The life and health insurance business is confident it can meet a significant part of the challenge in an effective and cost-efficient manner.

The most important thing you can do is to remove the inequities in the tax laws and make it clear that long-term care insurance is treated like all other health insurance. Thank you, Mr. Chairman, for the opportunity to present our views. We look forward to working with you and the Commission.

[The prepared statement of Mr. Schweiker follows:]

Statement
# of the
American Council of Life Insurance

On

PRIVATE LONG TERM CARE INSURANCE

Presented by

Richard S. Schweiker
President

Before the
Bipartisan Commission
on Comprehensive Health Care

October 5, 1989

Good morning Mr. Chairman and Members of the Commission. My name is Richard Schweiker. I am President of the American Council of Life Insurance. I am accompanied today by Stephen Kraus, Senior Counsel - Pensions at the ACLI.

I am pleased to testify today on behalf of the American Council of Life Insurance about the life and health insurance businesses' efforts to address a critical gap in this country's economic safety net for our elderly citizens. I refer to the overwhelming costs of long-term care in nursing homes and at home. There is currently no program, either public or private, which provides protection to most people against the devastating financial impact these costs can have.

The insurance industry believes the most effective way to solve this problem is through a creative partnership between the public and private sectors. My comments today are limited to one aspect of this partnership: modification of the current tax law in order to create an environment that will permit and encourage insurers to develop products that will provide long-term care protection and will help make it possible for employers and individuals to purchase these products.

The ACLI is the major trade association of the life insurance industry, representing 640 life insurance companies. Together, our members hold approximately 94 percent of the life insurance in force in the United States and approximately 94 percent of the assets of life insurance companies.

I. LONG-TERM CARE

Long-term care includes a wide range of medical and support services for people who suffer physical or mental disorders causing functional limitation or disability and who therefore need assistance for an extended period. The responsibility for providing long-term care assistance ranges from the individual and family to the government through the Medicaid program for those unable to provide for themselves.

Long-term care is the major source of significant medical expense paid for directly by individuals and their families today, particularly the elderly. About 1.3 million elderly, or four percent of the population 65 or older, receive long-term care in nursing homes. An additional 5.3 million receive long-term care in their homes or in other settings. The number of elderly needing long-term care is expected to increase by nearly 50 percent by the year 2000, before even the oldest baby boomers reach retirement age.

Private long-term care insurance can assist in providing protection against the overwhelming and mostly uncovered costs of long-term care. As the report to Congress and the Secretary by the Task Force on Long-Term Care Policies of the U.S. Department of Health and Human Services, dated September 21, 1987 states at page 1: "Private long-term care insurance gives individuals the opportunity to retain choices and develop a flexible, planned response to a potentially ruinous event ... Insurance offers the most cost effective, collective approach to meeting financial risks that often devastate individuals."

The number of companies developing long-term care insurance products, the number of individuals covered and the variety of products being developed, is increasing. Today, more than 100 companies are offering long-term care health insurance policies covering 1.3 million individuals. This compares to 75 companies and 815,000 individuals in 1987. Also, many life insurance companies are either offering or developing accelerated death benefit policies. The extent of coverage still remains quite small, however, relative to the potential.

An important factor that is inhibiting even faster growth of a private long-term care insurance market is the uncertain tax treatment of long-term care policies to (1) employers and their employees who may want to add long-term care protection as an employee benefit; and (2) individuals who will receive long-term care benefits.

II. CURRENT LONG-TERM CARE INSURANCE CONTRACTS

Initially, long-term care policies were only marketed on an individually-purchased basis, but now are increasingly being offered through employer-sponsored programs. The tax laws should be clarified to encourage the rapid development of this latter type of program since such programs will permit a large number of people to obtain protection against long-term illness costs.

The employer-based programs currently being marketed by our industry have a level individually determined premium which is guaranteed renewable. The insurer may not cancel the policy (except for non-payment of the premium) and the individual's premium will not increase regardless of his age or physical condition. If an employer terminates sponsorship or the individual leaves the group covered by the policy, the insurer guarantees that each individual will have the right to continue the coverage provided under the policy at the same premium. Although these policies currently do not contain any cash values, several companies are looking into whether such a product can be developed.

Another important development is that life insurance companies are designing a new generation of life insurance policies that permit the death benefit to be accelerated in response to the growing need for more comprehensive health care coverage. This cost-effective approach uses a life insurance policy as the foundation to provide long-term care benefits. Such coverage may be included as part of a life insurance policy at issue or added as a rider to an existing policy (hereinafter referred to as "riders"). Providing this coverage under a life insurance policy eliminates the administrative costs of a separate contract, enables the company to coordinate design of contract benefits to prevent coverage overlap, and insures against lapse of the coverage by permitting policy loans to pay premiums not otherwise paid by the policyholder when due. More importantly, however, is the cost savings inherent in utilizing the value of the death benefit and cash value of the underlying life insurance policy to provide the long-term care benefits.

A long-term care rider may provide for the payment of a certain percent of a policy's death benefit each month the insured requires long-term care. Such payments reduce both the policy's cash value and death benefit in a predetermined amount. Under another policy design, the policyholder has the option of receiving a lower payment based only on the excess of the death benefit over the cash value of the policy. Under this option, only the death benefit decreases each month by the amount paid.

Like long-term care health insurance policies, long-term care riders provide payments when an insured receives health or medical care services that are prescribed by a physician or other licensed health practitioner including such services for care resulting from a physical or mental impairment that makes the insured unable to perform one or more activities of daily living. The activities of daily living generally include: (1) Bathing; (2) Dressing; (3) Toileting; (4) Eating; (5) Transfer - the ability to move in or out of a bed or chair; and (6) Mobility - the ability to walk or move in a wheelchair on a level surface.

I believe an example of a particular long-term care rider would be helpful.

Assume long-term care payments begin under a policy purchased by an individual with a $100,000 death benefit and a $10,000 cash value. The first monthly payment equals $2,000 -- that is, two percent of the death benefit. Both the death benefit and the cash value would be reduced by two percent so that after the first payment the death benefit and cash value will be $98,000 and $9,800, respectively. Under this particular policy, the policyholder has the option of keeping the cash value intact by choosing to receive a lower payment of $1,800, resulting in reduction of only the death benefit to $98,200 and leaving the cash value at $10,000.

III. NEEDED CHANGES IN THE TAX LAWS

In order to make it possible for insurers to market long-term care products successfully, the insurance industry believes that several clarifications and changes are needed in the current tax law respects both long-term care health insurance policies and long-term care riders under life insurance policies:

(1) Long-term care benefits. Long-term care benefits paid under life or health insurance policies should be treated like health insurance benefits, and thus, excludable from the income of the policyholder.

(2) Premiums for long-term care benefits. Amounts paid to an individual by reason of coverage under a long-term care policy should constitute payment for expenses incurred for medical care and therefore any premium for such coverage should be deductible just as premiums for other policies covering medical expenses are deductible.

(3) Inclusion of long-term care insurance in a cafeteria plan. Coverage under a long-term care insurance policy should be allowed as a benefit under the cafeteria plan provisions, thereby allowing employees to elect such coverage to be paid from the available pool of dollars.

(4) Treatment of long-term care contributions under certain employer programs. Contributions made by an employer on behalf of its employees for benefits

under a long-term care insurance policy should not be includible in the employees' income.

(5) Use of IRA assets, pension payments, or life insurance cash values to purchase long-term care insurance. The use of IRA assets, proceeds from qualified pension or profit sharing plans, or proceeds from annuity, endowment, or life insurance contracts to pay for long-term care insurance should be allowed without a tax liability, even though such distributions might otherwise be taxable.

(6) Exchanges of life insurance or annuity contracts for long-term care insurance contracts. Individuals with accumulated cash values in life insurance or annuity contracts should be allowed to exchange such contracts for long-term care insurance without incurring a tax liability.

(7) Tax credit for long-term care insurance. Either in lieu of, or coordinated with, the exclusion of IRA, pension or cash value proceeds when used to purchase long-term care insurance, a refundable tax credit should be provided for lower-income individuals who purchase long-term care insurance.

(8) Definition of life insurance. It should be made clear that the presence of a long-term care rider does not alter the status of the basic policy as one of life insurance for purposes of the tax law. Also, policyholders should be allowed to pre-fund the accelerated death benefits (e.g. by paying the premiums on a level basis).

IV. OTHER CONTRACTS THAT CAN PROVIDE LONG-TERM BENEFITS

In addition to life insurance policies or riders that permit death benefits to be used for long-term care expenses, insurers have also designed riders that provide for payment of all or a part of the death benefit in the event of the onset of a specified dread disease or terminal illness. A dread disease rider provides payments when the insured has a specified disease or illness such as heart attack, coronary by-pass, stroke, cancer, renal failure or liver transplant. A terminal illness rider provides payments when an insured suffers a disease that will end life in a relatively short time period. For example, the State of Colorado has recently enacted a statute that permits a life insurance company to offer a rider that provides benefits for care when the insured is diagnosed as having a terminal case of AIDS.

The benefits paid under such riders should receive the same tax treatment as benefits paid under long-term care riders. They perform virtually the same function and therefore, like payments under long-term care riders, payments under terminal illness or dread disease riders should qualify for tax purposes as health insurance benefits.

V. BENEFITS AVAILABLE WHEN POLICIES LAPSE

At this point, Mr. Chairman, I would like to make a few comments with respect to the inclusion of nonforfeiture and similar values in long-term care policies and to the tax treatment that should be given to such benefits. These comments relate to insurance purchased by individuals, either on their own or under the sponsorship of their employer.

Nonforfeiture values are common in life insurance policies when premiums are paid in a level amount each year or under some other schedule which avoids sharply increasing premiums at older ages when insurance costs are highest. Any such premium schedule involves an element of prepayment and the nonforfeiture value is the settlement that will be made with the policyholder if he or she elects to stop paying premiums during the term of the policy. The States generally require such values in life policies. Some questions have, however, been raised about the tax treatment of such benefits in long-term care policies.

Level premiums based on the age at which coverage is purchased will undoubtedly be a necessary part of an enhanced long-term care insurance market. Policyholders will, in this fashion, be able to begin making payments for coverage during their income producing years and avoid having to pay prohibitively high premiums in their older years when protection is most needed.

Such level premium policies will inevitably have to include cash values or other nonforfeiture values. These values will be particularly important for relatively younger policyholders. This is a crucial group to encourage to purchase protection since the annual premiums will be lower and more manageable than if they waited later in life to buy a policy.

Our members are developing nonforfeiture features that range from a cash surrender feature to features which provide for continued coverage after premiums stop, such as extended term insurance or reduced paid-up insurance. Several features may be available in the same policy. In addition, some companies are providing other types of product features that are not technically nonforfeiture values, such as a return of premium feature. A brief description of the various benefits either being offered or contemplated by our members follows. It should be noted that the examples given do not exhaust the possible arrangements currently being offered.

Nonforfeiture Features

1. Cash Surrender - Under this feature, a policyholder surrenders the policy to the insurer in return for the policy's cash surrender value. The policyholder may determine that he or she may no longer need the policy, or may acquire similar coverage in another way. For example, the policyholder may wish to use the cash surrender value to buy into a continuing care retirement community which provides all the services that older people need from the day they arrive until they die. Without a cash surrender value option, the cost of long term care may be duplicated on entry into the CCRC.

2. Extended Term Insurance - Under this feature, upon discontinuation of premium payments, insurance would be extended for such period as the value of the policy would provide.

3. Reduced Paid-Up Insurance - Under this feature, upon discontinuation of premium payments, the policyholder would receive paid-up insurance in whatever amount the value of the policy would purchase. One company is already marketing a long-term care policy with a reduced paid-up option under which the policyholder would have paid up benefits of thirty percent after 10 years with an

increase in the paid-up benefit of an additional 3% a year up to a maximum of 75% of the benefit under the policy.

Other Features

1. Premium Refund - Under this feature, the policyholder would receive a refund of premium, possibly with interest, under certain circumstances. For example, one company is currently marketing a product which would return the entire amount of premium paid upon the death of the policyholder prior to age 65 if no claims were made under the policy. Another company would return, at the time of lapse or death of the policyholder, one-half of the premiums paid prior to age 65 provided the policy had been in force for at least five years and no benefits had been paid under the policy. Still another company would return the amount of the premium paid less claims made under the policy upon the death of the policyholder, if the policy had been in force for at least 5 years.

2. Fund Held By Insurer Under Group Policies - There are contracts that are held by employers or associations that cover a group of participants or certificate holders. Such contracts may provide that a fund held by the insurer with respect to the group policy will be transferred to another carrier if certain conditions are

> met. Cash would not be returnable to either the group policyholder or to any participant in the group plan. The transfer of the fund balance for the benefit of the certificate holder is intended to enable a successor carrier to continue essentially the same benefit structure at the same entry age premium levels. In the absence of the application of the fund in this manner, the individual certificate holders would be unable to obtain the same coverage at their original premium rates (if at all) due to their increased age and probable deteriorated state of health since they first became covered under the long-term care contract.

Providing nonforfeiture values and similar features in long-term care policies would encourage consumers to acquire the coverage on a level premium basis at early ages. Long term care benefits are most likely to be needed later rather than sooner. Without such values, if the insured's future circumstances require a change in coverage, or the policyholder dies, the difference between what the policyholder contributed and the cost of the protection up to that time, would be lost. It should be made clear that the provision of nonforfeiture values in long-term care insurance policies will not result in adverse tax consequences to the policyholder. Any other approach would damage the rate of growth of such coverage which is badly needed.

VI. CURRENT LEGISLATION

We are pleased that several bills have been introduced that favorably deal with one or more of the issues outlined above. The most thorough treatment of these tax issues is contained in H.R. 2499, a comprehensive long-term care bill introduced by Representative Barbara Kennelly and, in a bill introduced by Representatives Gradison and Kennelly, "The Long-Term Care Insurance Promotion Act of 1989," H.R. 1010. The latter bill deals exclusively with clarifications and changes to the current tax law in order to encourage the development and purchase of long-term care insurance policies. We strongly support the efforts of Representatives Gradison, Kennelly and others who have introduced legislation to clarify and modify the tax law as it applies to long-term care insurance.

VII. CONCLUSION

The problem of long-term care is a critical issue for the nation. Favorable clarification and change of current tax law with respect to long-term care insurance policies will go a long way towards addressing this problem and encouraging insurers to develop an extensive, private long-term care insurance market. Moreover, such action will encourage individuals to purchase long-term care insurance at younger ages when the price is more affordable and will stimulate employers to provide coverage to their employees where the potential for reaching the most people is greatest. Finally, allowing individuals to use current accumulated assets on a tax-free basis to purchase long-term care insurance will help those individuals who have a fairly immediate need for long-term care protection.

Thank you, Mr. Chairman, for the opportunity to present our views. We look forward to working with you and the Commission to develop legislation that will effectively solve the long-term care problem facing us.

Chairman ROCKEFELLER. Thank you very much. Ms. Shearer?

STATEMENT OF GAIL SHEARER, MANAGER, POLICY ANALYSIS, CONSUMERS UNION

Ms. SHEARER. Thank you. Mr. Chairman and members of the Pepper Commission, Consumers Union appreciates the opportunity to present our views on the issues of increasing access to health care and long-term care to all Americans. Consumers Union has supported the principle of extending access to high quality health care to all Americans for over 50 years.

We are still trying to come to grips with the implications of yesterday's House vote on the Catastrophic Act, when an obvious and disturbing message from the vote is that senior citizens with more resources are unwilling to lend a hand to senior citizens with less resources.

Another message is that middle- and high-income senior citizens would prefer a long-term care program to the Catastrophic Act. We wonder whether they realize that a comprehensive long-term care program will cost about 10 times the cost of the Catastrophic Act.

Efforts to address health care gaps incrementally are failing. Among the casualties of this failure is cost control, which is extremely difficult to achieve when the health care system is fragmented. We are straining to put a positive light on this week's events. One constructive reaction to them would be renewed efforts to stimulate debate on these important issues, just as this Commission is doing.

Hopefully the leadership that this Commission can provide will guide the Congress into a health financing program that will attract broad-based support. The focus of today's hearing is long-term care, a key component of the country's health care crisis.

In my testimony today, I will briefly describe many of the reasons why Consumers Union does not believe that the private long-term care market is capable of solving the Nation's long-term care problem.

I will also present 10 consumer-oriented parameters that should guide the Commission's policy decisions on long-term care, alternative long-term care programs at varying budget levels, and options for financing these alternatives.

Consumers Union believes that the private market cannot be expected to solve the Nation's long-term care problem for a number of reasons. To save time, I will list the problems and refer you to my written statement for more explanation.

Key inadequacies of the private long-term care insurance market are: unavailability to people with existing health conditions; fine print that restricts benefits—for example, covering only skilled or intermediate, not custodial, care; use of gatekeeping techniques such as prior hospitalization that severely limit protection; failure to protect adequately against inflation; inability to provide protection to children and young disabled adults; diversion of a large share of money to pay for administrative costs, marketing costs and profits; incentives for companies to underprice their so-called level premium policies in the early years; unscrupulous practices such as post-claims underwriting; and finally, the inability to protect a large share of the population because of the high cost.

Therefore, we recommend that this Commission reject options that would promote private long-term care insurance by preferred tax treatment for individuals or by tax preferences. This type of approach would inevitably collect tax revenues from a broad range of income groups and provide additional private long-term care insurance with limitations noted above to relatively high income people.

Consumers Union believes that the Government needs to take an active role in solving the long-term care problem. The parameters that should guide development of a social insurance program are the program should protect people of all ages, the program should be financed progressively, the program should be comprehensive and universal covering nursing home and home care, without building on the present welfare-based system.

The program should be self-funded. Administrative costs should be minimized. Cost-sharing should be an integral part of the program, but should not impose undue hardship. Cost control and quality control should be built into the program. Costs should be shared equitably between generations. Regulations of private markets should be effective and strictly enforced. Finally, public costs should be minimized while meeting consumers' needs.

It would be relatively easy to develop a long-term care program if unlimited money were available. The challenge facing this Commission and the Congress will be to shape a long-term care policy in the context of the huge budget deficit.

Our recommended programs for different budget levels follow. If virtually no new Federal money can be devoted to long-term care, Consumers Union recommends that a voluntary, long-term care insurance policy be offered through Medicare, part C. If $10 billion can be spent to finance long-term care, then Consumers Union recommends it be spent primarily to finance a comprehensive home health care program for people of all ages, coupled with the voluntary long-term care policy for nursing home coverage.

If $20 billion were available for long-term care, then Consumers Union recommends that the program include comprehensive home health benefits for people of all ages, nursing home coverage for the first 6 months of care, and a voluntary insurance program for long-term nursing home stays available through Medicare.

A $50 billion long-term care program could include a comprehensive home health care benefit, as well as a comprehensive nursing home benefit. The long-term care program could be financed by uncapping the ceiling on the Medicare portion of the payroll tax, increasing gift and estate taxes, charging people over 65 a modest premium, a broad-based payroll tax, and/or an income tax surcharge.

Consumer-oriented solutions to the long-term care program are available with different price tags. Consumers Union urges this Commission to develop a comprehensive proposal to assure people of all ages access to both basic health care and long-term care.

We're eager to help you meet this challenge. Thank you very much for the opportunity to testify.

[The prepared statement of Ms. Shearer follows:]

Consumers Union
Publisher of Consumer Reports

Testimony of

GAIL SHEARER

MANAGER, POLICY ANALYSIS

CONSUMERS UNION

before

THE PEPPER COMMISSION

UNITED STATES BIPARTISAN COMMISSION

ON COMPREHENSIVE HEALTH CARE

hearing on

LONG-TERM CARE FINANCING

October 5, 1989

SUMMARY OF CONSUMERS UNION'S TESTIMONY ON FINANCING OF LONG-TERM CARE

Consumers Union has major concerns about the ability of the private long-term care insurance market to meet consumers' needs. Some key problems with the private market include:

- Unavailability to people with existing health conditions;
- Fine print that restricts benefits;
- Use of "gate-keeping" techniques such as "prior hospitalization" that severely limit protection;
- Failure to protect adequately against inflation;
- Inability to provide protection to children and young disabled adults;
- Diversion of a large share of the money to pay for administrative costs, marketing costs, and profits;
- Incentives for companies to underprice their so-called "level premium" policies in the early years;
- Unscrupulous practices such as "post-claims underwriting," when companies check a policyholder's medical history only after a claim is filed; and
- Inability of the protect a large share of the population because of the high cost.

Parameters to guide the ideal long-term care program include:

- coverage to protect people of all ages;
- progressive financing;
- comprehensive and universal coverage;
- a self-funding requirement;
- minimization of administrative costs;
- cost-sharing that does not impose undue hardship;
- built-in cost control and quality control;
- equitable cost-sharing between generations;
- effective regulation of the private market; and
- minimization of public costs while meeting consumers' needs.

Consumer-oriented long-term care programs are available with different price tags.

- If virtually no federal money were available, a voluntary long-term care insurance policy could be offered through Medicare (Medicare Part C);
- A $10 billion program could offer home health care coverage to people of all ages, with cost-sharing for people with income over 200 percent of the poverty level;
- A $20 billion program could offer home health care benefits and nursing home coverage for the first six months of care, with sizable cost-sharing. Coverage for longer nursing home stays could be provided through a voluntary public program;
- A $50 billion program would allow for a comprehensive home health care benefit and nursing home benefit.

A long-term care program could be financed by: (1) uncapping the ceiling on the Medicare portion of the payroll tax; (2) increasing gift and estate taxes; (3) charging people over 65 a modest premium; (4) a broad-based payroll tax; and/or (4) an income tax surcharge.

Mr. Chairman and members of The Pepper Commission, Consumers Union[1] appreciates the opportunity to present our views on the issues of increasing access to health care and long-term care to all Americans. Consumers Union has supported the principle of extending access to high quality health care to all Americans for over 50 years. In 1939, **Consumer Reports** noted that forty million Americans received inadequate medical care and called for enactment of the Wagner National Health Bill, which would have been a "cornerstone for a national health program."[2] In 1946, **Consumer Reports** supported the Wagner-Murray-Dingell Bill, which would have established federal compulsory health insurance.[3] In 1975, **Consumer Reports** published a comprehensive comparison of five proposals for "national health insurance" and established five goals that a national health insurance plan must meet to serve the consumer interest.[4] (I have attached a copy of this article to my testimony, Attachment A.) The goals we defined fourteen years ago are worthy of repetition. They are:

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[1] Consumers Union is a nonprofit membership organization chartered in 1936 under the laws of the State of New York to provide information, education and counsel about consumer goods and services and the management of family income. Consumers Union's income is derived solely from the sale of **Consumer Reports**, its other publications and films. Expenses of occasional public service efforts may be met, in part, by nonrestrictive, noncommercial contributions, grants and fees. In addition to reports on Consumers Union's own product testing, **Consumer Reports**, with approximately 4 million paid circulation, regularly carries articles on health, product safety, marketplace economics, and legislative, judicial, and regulatory actions which affect consumer welfare. Consumers Union's publications carry no advertising and receive no commercial support.

[2] The Wagner Bill & Mr. Gannett," **Consumer Reports**, April 1939, p. 20 and "By Popular Demand," **Consumer Reports**, February 1939, p. 32.

[3] "Bureaucracy in Medicine?," **Consumer Reports**, April 1946, pp. 110 - 111.

1. Everyone's health-care needs should be covered, and the entire population should be included within the system.
2. There should be no connection between a patient's income and the extent or quality of care dispensed by doctors, hospitals, and others.
3. The plan should be financed progressively and in a manner open to public scrutiny.
4. The program should provide incentives for efficiency, control over the cost and quality of services, and encouragement of alternative or innovative systems for delivering health care; and
5. The administrators of the program should be accountable to the public, and consumers should have a voice in administration.

During the past 50 years, health care expenses (as a percent of gross national product) have grown rapidly. In 1940, national health expenditures were 4.0 percent of GNP.[5] The percent rose to 8.3 in 1975, and to 11.1 in 1987.[6] The corresponding figure (in 1986) for Britain is 6.2 percent, for Canada is 8.5 percent, and for Germany is 8.1 percent.[7] If present trends continue, health care will consume 15 percent of GNP in the year 2000.[8] It is clear that waiting longer is not going to make the problem any easier to solve. This is not a problem that will go away by itself if Congress fails to act.

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[4] "National Health Insurance: Which Way to Go?" **Consumer Reports,** February 1975, pp. 118 - 124.

[5] Robert R. Henderson, M.D, Health Care in the United States, Metropolitan Insurance Companies, 1982, p. 15.

[6] Source Book of Health Insurance Data, Health Insurance Association of America, 1989, p. 49, quoting U.S. Department of Health and Human Services, Health Care Financing Administration, **Health Care Financing Review,** Winter 1988.

[7] Ibid., p. 48.

The focus of today's hearing is on **long-term care**, a key component of the country's health care crisis. Consumers Union has been active on this issue in recent months. In May 1988, **Consumer Reports** rated 53 private long-term care insurance policies (Attachment B). This month's issue of **Consumer Reports** updates the earlier article (Attachment C). In January of this year, Consumers Union issued the report: Long-Term Care: Analysis of Public Policy Options, which analyzes many of the issues that this Commission is addressing. I have attached copies of the **Consumer Reports** articles to my testimony and have submitted the report for the record.

In my testimony today, I will describe many of the reasons why Consumers Union does not believe that the private long-term care market is capable of solving the nation's long-term care problem. I will also present some of the key reasons why Consumers Union supports a social insurance solution to long-term care, ten consumer-oriented parameters that should guide the Commission's policy decisions, alternative long-term care programs at varying budget levels, and options for financing these alternatives.

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[8] For the Health of a Nation: A Shared Responsibility, Report of the National Leadership Commission on Health Care, Health Administration Press Perspectives, Ann Arbor, Michigan, 1989, p. 3.

ROLE OF THE PRIVATE LONG-TERM CARE INSURANCE MARKET

Consumers Union believes that the private market can not be expected to solve the nation's long-term care problem for a number of reasons. Companies reject as many as 30 percent of applicants, those with higher than average health risks. Policies are expensive, costing up to $100 per month for a 65-year-old, and much more for older applicants. Policies often restrict benefits for certain types of care (e.g., custodial), and consumers seldom fully understand the implications of the fine print in the contracts. "Gate-keeping" techniques, whose role is to screen worthy beneficiaries from those who do not qualify for benefits are imperfect; while many policies are turning away from "prior hospitalization" requirements (which had the effect of denying protection to roughly 60 percent of nursing home entrants), many are using "activity of daily living" (ADL) screens. ADLs look at a patient's ability to perform routine daily activities such as eating and bathing. Even ADLs are far from perfect. One problem with ADLs is that many people with Alzheimer's Disease do not have serious ADL limitations. Another problem is that definition and measurement of ADLs can vary, resulting in a large variation (45 percent) in how many people in a community with serious ADL limitations actually qualify for a policy.[9]

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[9] Joshua M. Wiener, Ph.D., "Standards for Private Long-Term Cared Insurance; How Tough and Whose Job?," Testimony before the Subcommittee on Health, Ways and Means Committee, U.S. House of Representatives, May 17, 1989.

Failure to adequately protect against inflation is another flaw of many policies. While more companies offer an inflation rider now than in 1988, many of the riders are limited. We do not believe that policies with modest (but limited) benefit increases protect adequately against inflation. For example, a policy with a 5 percent per year increase for 10 years (less if the policyholder reaches a certain age) leaves a 20-year policyholder with inadequate protection against high inflation levels. A 7 percent per year inflation rate in policy years 10 through 20 would cut the policy benefits in "real" terms in half.

Another problem is the typical company policy of not providing a refund in the event the policyholder discontinues the policy.[10] Policyholders who drop their policy, perhaps to buy a better policy, are typically out of luck. We believe that policyholders who drop their policy after a certain amount of years of paying premiums should be eligible for some sort of compensation (e.g., a cash refund or a reduced benefit), since early year premiums are used to subsidize later year risks.

The private market is not well suited to insuring the long-term care needs of people under age 65. At this Commission's last hearing, you heard the compelling stories of a family who struggles to meet the daily needs of a husband crippled by multiple sclerosis and of a family whose child requires round-the-clock access to medical care because of a birth defect. Long-term care insurance is unable to help families like these who are in need today, or other young families who are at risk of having long-term care needs before the age of 65.

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[10] In insurance parlance, this issue is referred to as "nonforfeiture values."

Furthermore, the private market is expected to divert 40 to 50 percent (or more) of premiums collected to cover administrative and marketing costs, and profits. In contrast, the Medicare system spends 97 percent of revenues on benefits.

Another deficiency of the private market is unfair pricing practices. Most long-term care policies are "level-premium" policies. This does not mean that premiums will remain level. It means that premiums will not automatically increase each year as the policyholder ages. Companies with "guaranteed renewable" policies are free to increase the so-called level premium if they increase it for everyone else in the state with the policy. This amounts to "bait, lock-in and switch" for consumers, who are forced to make a purchase decision without knowing the cost in future years. This leads to strange incentives for insurance companies. Companies have a strong incentive to underprice the policy initially in order to attract customers, and then raise premiums in later years, once consumers are locked in.

Unscrupulous insurance company and agent practices have also created major problems for consumers. This month's issue of **Consumer Reports** tells the story of three victims of the troubling practice of "post-claims underwriting" -- the practice of checking a policyholder's medical history only after a claim is filed, instead of when an application is taken. It is very difficult for a consumer to predict at the time of purchase whether the company is likely to honor a legitimate claim made in the future.

All of these considerations affect the appropriateness of private long-term care insurance for individual consumers. From a public policy perspective, however, there is one overriding consideration that affects whether the private market can solve the problem -- affordability. Even under optimistic assumptions about people's willingness to buy policies, the Brookings Institution estimates that a fairly limited private insurance policy could be purchased by only 25 percent of the elderly by the year 2018 and that such coverage could make an insignificant reduction in Medicaid long-term care expenditures, reducing the number of nursing home patients whose expenses are covered by Medicaid by only 2.3 percent in 2018.[11]

Therefore, we recommend that this Commission reject options that would promote private long-term care insurance by preferred tax treatment for individuals or by tax preferences. This type of approach would inevitably collect tax revenues from a broad range of income groups, and provide additional private long-term care insurance (with the limitations noted above) to relatively high income people.

Several states are planning demonstration projects that will liberalize the Medicaid spend-down requirement for people who purchase state-sanctioned long-term care insurance. These projects face (at least) two major challenges: improving the performance of the private market so that the state is not in the position of encouraging the purchase of a flawed product, and assuring equitable treatment across income groups.

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[11] Alice M. Rivlin and Joshua M. Wiener, Caring for the Disabled Elderly -- Who Will Pay,? The Brookings Institution, 1988, p. 77 and p. 80.

SUPPORT FOR SOCIAL INSURANCE PROGRAM

Consumers Union believes that the government needs to take an active role in solving the long-term care problem. The parameters that should guide development of a social insurance program are:

1. The program should protect people of all ages;
2. The program should be financed progressively;
3. The program should be comprehensive and universal;
4. The program should be self-funded;
5. Administrative costs should be minimized;
6. Cost-sharing should be an integral part of the program, but should not impose undue hardship;
7. Cost control and quality control should be built-in to the program;
8. Costs should be shared equitably between generations;
9. Regulation of the private market should be effective and strictly enforced; and
10. Public costs should be minimized while meeting consumers' needs.

Each of these parameters is explained in detail in Consumers Union's January 1989 report, Long-Term Care: Analysis of Public Policy Options. I would like to briefly expand on three of them.

The program should protect people of all ages.

A long-term care program should cover people of all ages, not just people over 65 years old. Many younger people are disabled or chronically ill. Approximately 40 percent of people who need personal assistance because of inability to perform one or more "activities of daily living" are under age 65.[12] Children and young adults are the people least likely to purchase private long-term care insurance, and are least likely to be able to plan ahead for future long-term care costs. The large costs involved make it necessary to turn to people under age 65 for at least some of the funding of a long-term care program; covering their long-term care risks will make the long-term care program more appealing as well as fairer to them.

The program should be comprehensive and universal.

The program should be comprehensive, covering both home health care costs and nursing home costs. It should be universal -- protecting all Americans at risk of needing long-term care on a mandatory bases.

One option that this Commission is considering is expanding Medicaid coverage of long-term care. This could be done, for example, by increasing the assets and/or income level that could be retained when qualifying for Medicaid. We certainly support the increased protection against spousal impoverishment that were included in the 1988 Medicare Catastrophic Coverage Act (P.L. 100-360).

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[12] Linda H. Aiken, "The Aging of America: Implications for State Policy," Building Affordable Long-Term Care Alternatives: Integrating State Policy, National Governors' Association, Center for Policy Research and Analysis, Washington D.C., April 1987, p. 11, quoted in "Long Term Health Policies," Report to Congress and the Secretary by the Task Force on Long-Term Health Care Policies, September 21, 1987, p. 18.

In the long-run, however, we believe the country should move away from a welfare approach to funding long-term care. The Medicaid share of nursing home costs is already high, 43 percent.[13] Even without a change in public policy, the increasing number of elderly would increase the Medicaid long-term care expenditures in the coming decades. The welfare approach is extremely inequitable. Since taxpayers already pay a large share of long-term care costs, public policy makers should understand why so many seek legal help to exploit loopholes to allow them (or their parents) to qualify for Medicaid. The Office of Inspector General of the Department of Health and Human Services describes some typical comments from state staff involved in transfer of assets that are related to Medicaid qualification:

> -- "People are starting to use a lot of fancy footwork to avoid losing the 'family fortune.'"
>
> -- "If an applicant or recipient is over assets, they can reduce their assets by buying any exempt or excluded asset and requalify for assistance . . . Families buy vehicles and even diamond pendants to qualify [exclude] the assets. Personal property is excluded so it can be given away at any time."
>
> -- "Many, many, many attorneys call on a daily basis looking for 'loopholes.' There are lots of welfare

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[13] Alice M. Rivlin and Joshua M. Wiener with Raymond J. Hanley and Denise A. Spence, Caring for the Disabled Elderly: Who Will Pay?, The Brookings Institution, Washington, D.C. 1988, p. 42.

> specialists who help people avoid welfare resource limits."[14]

It does not seem fair to reward relatively sophisticated families with qualification for long-term care coverage, and leave others who comply with the spirit of the program without any protection. We believe that a social insurance program that protects all Americans against the devastating costs of long-term care is the best way to correct these inequities.

Costs should be shared equitably between generations.

The recent controversy over the catastrophic bill highlights the challenge Congress faces when trying to achieve an equitable sharing of costs between generations. The costs of long-term care (averaging $1300 per person over age 65)[15] are too high to be borne by the elderly alone. Since we believe that coverage of people of all ages is a necessary component of a long-term care program, it follows that people under age 65 should share in the bill. The least painful way for an individual to pay his or her own long-term care risk is in small payments spread throughout his or her entire working life. It is too late for people who are over 65 to do this. People over 65 should share the cost of a long-term care program through premiums, increased estate taxes, and cost-sharing.

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[14] Richard P. Kusserow, Inspector General, Department of Health and Human Services, **Medicaid Estate Recoveries**, June 1988, p. 12.

[15] Alice M. Rivlin, Joshua M. Wiener, et. al., "Who Should Pay for Long-Term Care for the Elderly?," The Brookings Review, (vol. 6, no. 3, Summer 1988), p. 6.

ALTERNATIVE LONG-TERM CARE PROGRAMS

It would be relatively easy to develop a long-term care program if unlimited money were available. The challenge facing this Commission and the Congress will be to shape a long-term care policy in the context of the huge budget deficit. The long-term care problem will soon be so critical that Consumers Union supports a comprehensive and universal social insurance program, even though we recognize that such a program will ultimately involve tax increases. Our recommended programs for different budget levels follow:

Extra Low Option

If virtually no new federal money can be devoted to long-term care, Consumers Union recommends that a voluntary long-term care insurance policy be offered through Medicare (e.g., Medicare Part C). Premiums would be charged to cover costs and ability to "buy into" the system would be limited to two to three defined age points (e.g., age 45, age 60) to reduce adverse selection. Premiums could be scaled to income with a cap to prevent losing upper income people from the system.

Low Option

If $10 billion can be spent to finance long-term care, then Consumers Union recommends it be spent primarily to finance a comprehensive home health care program for people of all ages. Congressman Pepper's approach, modified to allow for modest cost-sharing by people with incomes greater than 200 percent of the federal poverty level, would be a useful starting point for discussion. A second element of this option would be a voluntary long-term care policy for nursing home coverage, similar to that described under the "extra low option" above.

Medium Option

If $20 billion were available for long-term care, then Consumers Union recommends that the program include comprehensive home health benefits for people of all ages (as described above in "Low Option," nursing home coverage for the first six months of care (with cost-sharing of 10 to 35 percent for people with incomes above 200 percent of poverty), and a voluntary insurance program for long-term nursing home stays, available through Medicare. This benefits package is essentially the same as that of Senator Kennedy's Lifecare Insurance Plan, which was introduced into the 100th Congress.

High Option

A $50 billion dollar long-term care program allows for the most comprehensive social insurance approach. The program could include a comprehensive home health care benefit as well as a comprehensive nursing home care benefit. Nursing home benefits could begin after one or two months, with cost-sharing around 20 to 35 percent. There would be no cost-sharing or waiting periods for people with income below 200 percent of the federal poverty level. A standardized private long-term care market could offer policies to cover cost-sharing and waiting periods.

FINANCING THE LONG-TERM CARE PROGRAM

Revenue needs vary with the option selected. If the "extra low" option is chosen, minimal revenues are needed and could be relatively easily collected through a small gift and estate tax surcharge. If $10 billion is needed to fund the "low option," Consumers Union recommends either a combination of a 10 percent gift and estate tax surcharge on assets over $200,000 and an increase in excise taxes on alcohol and cigarettes, or uncapping the health insurance portion of the payroll tax and a small premium for people over 65. To fund a $20 billion "medium option," we would use a combination of increased payroll taxes, higher premiums, and the gift and estate tax surcharge. Finally, to fund a $50 billion program, we recommend a combination of payroll taxes, gift and estate taxes, premiums, and either an income tax surcharge or broad based payroll tax. Table X-2 of our report (p. 104) summarizes our financing recommendations.

Consumer-oriented solutions to the long-term care program are available with different price-tags. Consumers Union urges this Commission to develop a comprehensive proposal to assure people of all ages access to both basic health care and long-term health care. We are eager to help you meet this challenge.

Thank you very much for the opportunity to testify today.

CU VIEWPOINT

ATTACHMENT A

National Health Insurance
WHICH WAY TO GO?

The United States is the only major industrial nation without a comprehensive national health insurance plan. For years, politicians, the health-care industry, organized labor, and ordinary consumers of health care have been debating whether such a plan was needed. Now a consensus appears to have developed. Democrats and Republicans, doctors and patients, hospitals and insurance companies—all agree that some form of national health insurance is indeed needed.

The question is: *What* form of national health insurance? The answer, likely to be provided by the new Congress, is of vital interest to consumers.

The national health insurance proposals now before Congress differ sharply in a number of key respects, including the extent of insurance coverage, the method of financing, and the mode of administration. In this report, CU will attempt to explain what these differences mean for consumers.

DIAGNOSING THE PROBLEMS

Runaway cost is generally considered the number-one problem in financing adequate medical services. Charges for personal health services, mainly doctor and hospital bills, have risen more rapidly in the past two decades than has any other component of the Consumer Price Index. Since 1950, the total index has risen 112.5 per cent; the medical-care component, 191.1 per cent. The cost of a day in the hospital has risen from an average of $16 in 1950 to $119 today.

Health expenditures now claim $105-billion a year, or 7.8 per cent of the gross national product. Despite that vast sum, Americans do not come off well in key statistical indicators used to measure the general health of a population. The United States ranks 13th in the world in infant mortality; 18th in male life expectancy at birth; and 11th in female life expectancy. Such environmental factors as dietary habits, exercise patterns, and smoking play an important role in those statistics. So do such factors as economic, social, and racial discrimination. But a rational means of financing adequate medical services is also vital to an improved general level of health.

Another major problem is inadequate insurance protection, especially among the poor. In 1972, only 36 per cent of persons under the age of 65 who earned less than $3000 were covered by any hospital or surgical insurance. Nor did wealthier individuals enjoy great protection. Only half the population had major medical insurance, and the typical limit of reimbursement was $5000. One private hospitalization policy in every three covered no more than 60 days' confinement. Insurance policies paid only 42 per cent of personal health-care expenditures. (While those statistics relate to 1972, they are the latest available, and they are believed representative of the insurance situation today.)

Health insurance coverage, in short, is nonexistent for many of the poor and inadequate for almost everyone else.

A third major problem is the chaotic system of financing health services. That system includes welfare programs (such as Medicaid), which vary widely in coverage and cost from state to state; private health insurance plans (purchased by employers, as part of employe fringe-benefit programs, or by individuals), which also vary widely in coverage and cost; and marriages of public financing with private health insurance administration, as in the Medicare program for the elderly. The system also includes "self insurance" for those unable to buy or acquire insurance, or willing to take a chance that someone, somehow, will take care of things when illness strikes.

Some results of the present system: Different levels of care for the poor and the nonpoor. Economic incentives that have resulted in a relative oversupply of physicians in suburban areas and a relative undersupply in the inner cities and in rural areas. A private insurance structure that tends to pay for (and thus encourage) expensive care of illness in hospitals, but usually fails to pay for (and thus may discourage) preventive care in doctors' offices.

WHAT CONGRESS IS CONSIDERING

There are a total of 23 bills before Congress, all of them loosely termed "national health insurance." But for the purposes of discussion they can be narrowed down to five main plans. We will sketch the general outlines of each. Later, we will discuss them in more detail as we match their specifics to what, in CU's opinion, are the most appropriate goals of consumer-minded national health insurance legislation.

AMA

A.M.A. PLAN. Two important health-industry organizations, the Health Insurance Association of America (H.I.A.A.) and the American Medical Association (A.M.A.), favor an approach that relies on voluntary purchase of private health insurance. Government would subsidize premium costs for the poor. Persons with higher incomes would be eligible for a tax credit under the A.M.A. plan and a tax deduction under the H.I.A.A. plan. Our discussion will concentrate on the A.M.A.'s proposal, called Medicredit, because it has the most support in Congress of any plan thus far put forward by a professional organization or insurance-industry group.

FORD

ADMINISTRATION PLAN. The Ford Administration, like the Nixon Administration before it, proposes to plug gaps in the existing insurance system at minimum cost to the Federal treasury. A standard insurance policy with broad benefits would be made available in three ways. First, states would help pay for the coverage as a replacement for the present Medicaid welfare program. Second, employers would purchase it from insurance companies for their employes. And third, the Social Security Administration would supply the coverage to the Medicare population.

L-R

LONG-RIBICOFF PLAN. Senators Russell B. Long of Louisiana and Abraham A. Ribicoff of Connecticut propose an expansion of Social Security to cover the costs of catastrophic illnesses, defined as an illness or illnesses entailing more than 60 days in the hospital or more than $2000 in doctor and other medical bills. Insurance companies would be encouraged to develop a standard policy to defray the sizable costs not met by the catastrophic plan. Medicaid would be replaced by a new, subsidized health plan for the poor.

K-M

KENNEDY-MILLS PLAN. This is a joint proposal of Representative Wilbur Mills of Arkansas, former chairman of the House Ways and Means Committee, and Senator Edward M. Kennedy of Massachusetts. It would expand the Social Security system to include a broad health-care policy for those under 65. Private insurance companies would process claims and pay bills on the Government's behalf, as in the present Medicare plan. Medicare would be retained for the elderly.

K-G

KENNEDY-GRIFFITHS PLAN. This proposal is named after its original sponsors, Senator Kennedy and former Representative Martha Griffiths of Michigan. The plan, sponsored this year by Representative James C. Corman of California, would establish a single, mandatory insurance program covering the entire population with comprehensive benefits—so-called "cradle-to-grave," or "womb-to-tomb," protection. The program would be financed from tax revenues. The Federal Government would operate it without aid from insurance companies.

HOW THE PLANS MEET CONSUMER GOALS

In CU's view, a national health insurance plan must meet five minimum goals in the consumer interest. We will state those goals as we see them, and describe how each of the plans mentioned above meets them—or fails to meet them.

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1. Everyone's health-care needs should be covered, and the entire population should be included within the system.

*In insurance terminology, that's called **universal** coverage. With universal coverage, the risk of loss from illness can be shared equitably. Coverage should be **mandatory**, not voluntary. Otherwise, those who most need coverage, the poor, are likely to risk, or be forced to risk, allocating their meager resources to more immediate needs, such as food. There should be a single policy and program for everyone **(a unitary plan)**, not several plans offering one set of benefits to the poor and another to the nonpoor. A unitary plan holds out certain benefits even for the nonpoor: It guarantees coverage between jobs, for example, and it protects against higher rates that may result from an illness in the family. But the basic argument for a unitary plan is social fairness. The inevitable outcome of separate programs is discrimination against the poor in the receipt of health services.*

AMA

A.M.A. PLAN. While everyone is eligible for Medicredit, enrollment would be voluntary, not mandatory. In addition, the plan is not unitary but has three tiers—Medicare for the elderly, Medicaid for the poor, and private policies for those with the foresight and the wherewithal to buy them.

FORD

ADMINISTRATION PLAN. Enrollment in the employe health insurance plan would be voluntary, not mandatory. There's only limited provision for insurance of workers between jobs. The plan is not unitary. Doctors would be allowed to charge more when they treat persons with employer-provided coverage than when they treat those with state-provided, low-income protection. That builds in an economic incentive to discriminate against treating poor patients.

L-R

LONG-RIBICOFF PLAN. Catastrophic coverage would be mandatory for persons insured under Social Security. Others, such as employes of state governments, would have to buy in. The plan is a combination of catastrophic coverage, voluntary private policies, and a Government policy for poor persons. It therefore does not provide the same coverage for everyone, and thus it is not a unitary plan.

K-M

KENNEDY-MILLS PLAN. Coverage would be mandatory but not quite universal. Certain divorcees, children, self-employed persons, students, and young persons newly entering the work force could be excluded. The plan is unitary—everyone would have the same coverage.

K-G

KENNEDY-GRIFFITHS PLAN. Coverage is universal and mandatory. The plan is unitary—the same coverage for all.

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2. There should be no connection between a patient's income and the extent or quality of care dispensed by doctors, hospitals, and others. *Financial hardship resulting from illness should be ended. Benefits should include: all hospital charges; doctor bills, whether incurred in the office or a hospital; preventive services, such as prenatal care, well-baby care, and eye examinations; short-term care for mental illness; and long-term nursing-home care. In insurance language again, these are called* ***comprehensive, balanced benefits.*** *Any "cost-sharing" between the insurance plan and the patient should be arranged in such a way that no patient is tempted to neglect needed care or is faced with financial hardship as a result of some medical need. Cost-sharing usually takes the form of a* ***deductible*** *(a minimum amount paid by the patient before insurance payments begin) or* ***coinsurance*** *(a percentage of the bill charged directly to the patient). It is argued that some form of cost-sharing is desirable to discourage overburdening the health-care system with trivial or unnecessary demands for service (see page 123).*

AMA

A.M.A. PLAN. Insurance policies would have to meet Federal standards for basic coverage, but very little preventive care is specified. Coinsurance is 20 per cent for the first $500 spent on certain expenses, such as emergency or outpatient hospital services, and physician care. There is a $50 deductible for each hospital stay. The deductible in a separate catastrophic expense plan is 10 per cent of taxable income.

FORD

ADMINISTRATION PLAN. Benefits include hospital care without limit, doctor and other medical services, prescription drugs, family planning, maternity service, well-care for preschool children, plus dental, eye, and ear care for children under age 13. With some limits, there would be coverage for mental illness, nursing-home stays, and home health services. But cost-sharing is stiff. Under the employer plan, for example, a family would be responsible for the first $150 of covered expenses per person (the deductible), up to $450 total for the family, plus $50 in prescription-drug expenses per person, and 25 per cent of all additional expenses (coinsurance) up to $1500. After the family paid $1500 out of pocket, the plan would pay all further bills. Cost-sharing is gradually reduced for poor persons under the state and Medicare programs. But the amount of cost-sharing appears sufficiently stringent to discourage some persons from receiving needed care—6 per cent of income for families with less than $2500 and 9 per cent of income for families earning between $2500 and $5000. And it could severely shock the budget of a middle-class family that is unfortunate enough to incur high medical and hospital expenses.

L-R

LONG-RIBICOFF PLAN. This program focuses on catastrophic expenses and ignores preventive care. Cost-sharing is minimal in the low-income plan but extensive in the catastrophic plan; a deductible of 60 days' hospitalization in one year before hospital and extended-care benefits begin; $2000 medical expense deductible per family; and 20 per cent coinsurance on medical expenses exceeding $2000 to a ceiling of $1000 in coinsurance. This means that health-care costs for a family could still total $9000 or more ($6000 for 60 days in the hospital, $2000 in medical expenses, and $1000 coinsurance). In our view, $9000 is a catastrophic expense in itself.

K-M

KENNEDY-MILLS PLAN. Policy benefits closely resemble the Administration Plan, but there's less cost-sharing. For a family of four with more than $8800 income, benefits would be subject to a deductible of $150 per person (not to exceed two deductibles per family) and 25 per cent coinsurance of covered charges up to a maximum of $1000 in family payments for any one year. The program pays everything after $1000. (Preventive services would not be subject to deductibles and coinsurance, and there would be a separate charge of $1 per prescription.) A family of four earning between $4800 and $8800 would be responsible for reduced copayments and deductibles, not to exceed 25 per cent of the difference between $4800 and actual family income. A similar family earning less than $4800 would pay nothing. The meaning of these formulas is that out-of-pocket maximums are lower under Kennedy-Mills than under the Administration plan ($1000 versus $1500), and low-income persons are totally subsidized by the Kennedy-Mills plan rather than facing substantial payments, as in the Administration proposal.

K-G

KENNEDY-GRIFFITHS PLAN. Benefits are the broadest and most comprehensive of any plan under consideration. The only significant exclusions are prescription drugs under certain circumstances, psychiatric care beyond stated limits, and adult dental care. The plan pays the entire cost of covered services, meaning that there would be no out-of-pocket deductibles or coinsurance for individuals to pay.

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3. The plan should be financed progressively and in a manner open to public scrutiny.

All the national health insurance proposals under consideration in Congress involve public spending. The money to finance the plan should be raised through a form of progressive taxation—those who can afford less should pay less, and those who can afford more should pay more. In addition, the cost of the program should be visible to the public, so that the public can decide through democratic processes the place of health insurance in national spending priorities.

AMA **A.M.A. PLAN.** This program would be financed in part by tax credits, which are *disguised* Federal expenditures, not visible ones. The remaining funding would be through general tax revenues used to buy insurance policies for poor people. We believe that invisible financing for the nonpoor will provide an incomplete and perhaps misleading view of the plan's costs.

FORD **ADMINISTRATION PLAN.** Financing for the coverage employers must offer employes is not progressive: premiums are the same regardless of an employe's salary. Nor is the financing visible: the premium payments go directly to insurance companies and therefore never show up in a budget open to public view.

L-R **LONG-RIBICOFF PLAN.** Financing would be by means of a payroll tax of 0.3 per cent at the start. A payroll tax is slightly regressive, since not all sources of income (rent, interest, dividends) are subject to the tax and not all earned income is subject to the tax. The welfare part of the plan would come out of general revenues, which are raised in a progressive manner.

K-M **KENNEDY-MILLS PLAN.** Financing would be by means of a 4 per cent payroll tax up to $20,000 earnings (employers would be responsible for at least 3 per cent and employes for no more than 1 per cent); a 2½ per cent tax on self-employment and unearned income up to $20,000; a 1 per cent tax on Aid for Dependent Children welfare income; state contributions; and general revenues. Financing, on balance, would be visible and roughly proportional to income, which is not quite the same thing as being progressive. (A progressive tax takes a higher percentage of higher incomes; a proportional tax takes the *same* percentage, regardless of income level.)

K-G **KENNEDY-GRIFFITHS PLAN.** Half of program costs would be financed from general tax revenues. The other half would come from a 3.5 per cent tax on employers' payrolls, a 1 per cent tax on employes' wages (and on unearned income) up to $15,000, and a 2.5 per cent tax on self-employment income up to $15,000. Financing is thus visible and progressive.

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4. The program should provide incentives for efficiency, control over the cost and quality of services, and encouragement of alternative or innovative systems for delivering health care.

The new system should end "cost-plus" payments to medical providers. (When a hospital or nursing home knows an insurer will pay all costs incurred, plus a premium, there is no incentive to control costs. Such institutions should be held to negotiated budgets and rewarded for their efficiencies.) Physicians who participate in the system should be paid according to fee schedules negotiated through their professional societies. The system should encourage formation of such alternate modes of practice as health maintenance organizations (HMOs), which CU reported on in October 1974. And it should subsidize the training of more health professionals, since more will be needed to provide appropriate care to everyone.

AMA **A.M.A. PLAN.** The proposal has no apparent provisions to encourage efficiency or control costs or quality, nor does it address any other parts of the above goal.

FORD **ADMINISTRATION PLAN.** Deductibles and coinsurance would be used to reduce demand for services and thus control costs. Physician review groups, called Professional Standards Review Organizations, or PSROs, would review medical services provided. HMOs would be encouraged. There would be fee schedules, but doctors would not be held to them. States would establish prospective reimbursement schedules for hospitals. (Prospective reimbursement is a method of encouraging hospitals to meet a budget and penalizing them for failure to do so.)

L-R **LONG-RIBICOFF PLAN.** Deductibles, coinsurance, and PSROs would be used much as in the Administration plan.

K-M **KENNEDY-MILLS PLAN.** Deductibles, coinsurance, and PSROs would be used in a manner similar to the Administration and Long-Ribicoff plans. HMOs would be encouraged, and hospitals and nursing homes would be held to prospective, negotiated budgets and rewarded with incentive payments when they saved money. Physician payments would be based on fee schedules negotiated with medical societies, but physicians could opt out of the program, charge more than the schedules, and still be reimbursed through the plan up to the limit of the fee schedule. The patient would then have to pay the remainder. Consultations and referrals would be necessary before certain surgical procedures could be performed, and payment would only be provided for surgery done by qualified specialists.

K-G **KENNEDY-GRIFFITHS PLAN.** There would be prospective budgeting for hospitals, nursing homes, and home health agencies. Reimbursement of physicians and other professionals would favor those who practice in HMOs or who locate in remote or deprived areas. National licensing standards would be established for practitioners. There would be regulation of major surgery. A special fund would finance the training of additional health professionals and encourage alternate modes of practice.

Continued on next page

5. The administrators of the program should be accountable to the public, and consumers should have a voice in administration.

The organization administering national health insurance will disburse tens of billions of publicly raised dollars each year. This organization should owe its allegiance to taxpayers, not to health-care providers. The administering organization should be accountable to the Congress and to consumers through well-defined review, grievance, and appeal mechanisms. Consumers should have a say at all levels of administration, preferably through elected representatives.

AMA **A.M.A. PLAN.** Insurance companies would administer the plan. They would be accountable only to state insurance departments, few of which have in the past distinguished themselves as advocates of the consumer interest. Consumers are provided no role in the A.M.A. scheme of things.

FORD **ADMINISTRATION PLAN.** This proposal would channel as much as $75-billion into the private health insurance industry. State regulation is provided for, as in the A.M.A. plan. There is no role for consumers in the Administration plan.

L-R **LONG-RIBICOFF PLAN.** Insurance companies would pay claims under contract to the Social Security Administration—the Medicare arrangement. Again, there's no role for consumers.

K-M **KENNEDY-MILLS PLAN.** Administration would be similar to Long-Ribicoff: insurance companies as middlemen for a revamped Social Security Administration. There's no provision for consumer involvement in policy-making or administration.

K-G **KENNEDY-GRIFFITHS PLAN.** The Department of Health, Education, and Welfare would be responsible for every aspect of the program under a five-member Health Security Board. Administration would extend downward to public regional and local organizations. Health insurance companies would have no role, meaning that most of them would be out of business. Consumers would constitute a majority of a national committee that would advise on general policy, on formulation of regulations, and on program operations. Consumers would also be involved at the regional, but not local, level of administration. Aggrieved consumers, and providers, would be entitled to hearings, appeals, and judicial review.

RECOMMENDATIONS

The only current national health insurance plans capable of fulfilling most of the goals stated above are, in CU's judgment, the Kennedy-Mills and Kennedy-Griffiths plans. As the debate warms up, you may well hear one or both of these plans described as "socialized medicine," just as Medicare for the elderly was so described during the years of debate that preceded its passage. Recognize such scare words as the political hyperbole they are; no plan before Congress proposes to make doctors and other health workers Government employes.

Fee schedules for physician services, however, would, in CU's view, be necessary under a national program—to control costs. Doctors should therefore be allowed the choice of participating or not participating in the program. Those who participated would accept the negotiated fee schedules. Those who did not participate could charge any amount. But CU strongly recommends that no part of the services of nonparticipating doctors be reimbursable under the new program. Patients who choose treatment from physicians or other health-care providers who decide not to participate in the national health insurance plan would have to pay the entire bill themselves.

That might cause inconvenience for some persons at first, until they learned which doctors they could not afford. But it's the only way CU sees to avoid the mistake made in the Medicare program. Under that program, doctors may choose to accept the Medicare fee schedule as payment in full or to bill the patient the difference between the Medicare payment and his or her customary fees. As a result, Medicare payments have become a floor for ever higher fees.

Cost is often raised in objection to a comprehensive Federal plan for national health insurance. But, for the most part, cost, like "socialized medicine," is a scare word.

THE PROBLEM OF COST

To start with, most cost estimates are unreliably partisan. The supporters of a plan estimate low; opponents estimate high. But when you see a price tag of, say, $102.7-billion attached to the Kennedy-Griffiths plan, or $79.6-billion to the Kennedy-Mills proposal, consider that such figures do not necessarily mean *new* spending for medical care. In fact, most of those multibillion-dollar price tags do not represent new spending but a *regrouping* into a single program of all those separate payments now made for private insurance premiums, out-of-pocket costs, and Medicare and Medicaid.

Thus, medical-care expenses per person now average $496 a year ($1984 for a family of four), divided among insurance premiums, out-of-pocket expenses, and tax contributions for Government health programs. Under the Kennedy-Griffiths plan, to take one example, that same $496 would go in tax payment to the national health insurance program. The program, in turn, would act as a single funnel for paying most bills now paid in a number of ways.

However, comprehensive national health insurance would result in additional, rather than just transferred, costs if it generated new demand for health services. If a national plan lowered financial barriers to care, and if people demanded, or doctors ordered, more treatment than before, then so-called "induced" costs would be incurred. In other words, there would be more units of service to pay for. There would also be inflation in existing costs if the supply of health workers was insufficient to absorb the new demand for service. The Department of Health, Education, and Welfare has estimated that annual induced costs would be $6.5-billion under the Administration plan, $9.3-billion under Kennedy-Mills, and $13-billion under Kennedy-Griffiths. (Estimates of induced costs are included in the chart below.)

What might such plans do to your tax bill? Let us consider the broadest proposal (Kennedy-Griffiths) with the highest induced cost ($13-billion). Let us further assume that all costs would be met by increased taxes of various sorts, none from a reordering of spending priorities, such as reduced military or space-program spending. Then the average American family, which now pays about $1200 in Federal income and Social Security taxes on $11,500 in gross income, would pay roughly $300 more in such taxes. More affluent families, those with incomes of $20,000, would find their average tax bill of $2600 increased by $600. (Before shuddering at so steep a tax increase, subtract from it anything you now pay, directly or as a fringe benefit, for health insurance. Then compare the net extra cost, if any, with differences in benefits between your present coverage and the broad Kennedy-Griffiths coverage.)

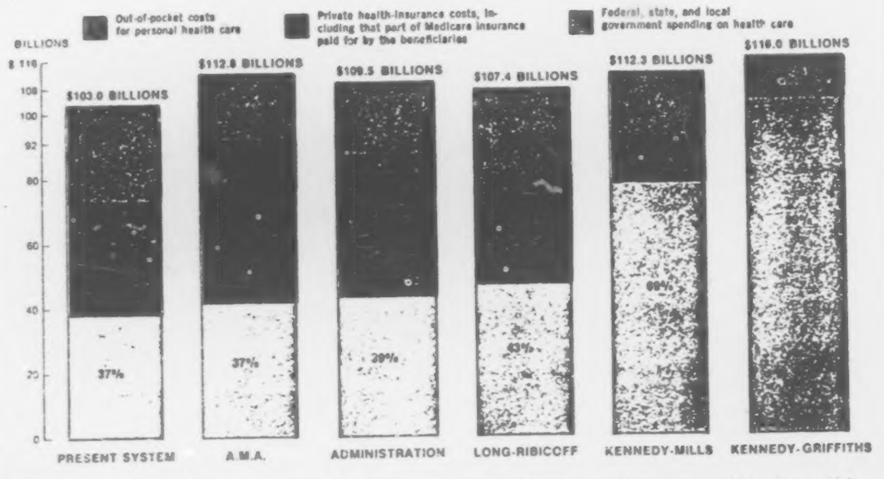
There could be another problem if most bills were paid by a Government program: elimination of price competition among health-care providers. If a Government program became the sole source of payment for health bills and paid every one in full, hospitals and other institutions would have no incentive to introduce efficiencies that lower price. Price competition, however limited it may now be, would give way to a uniform, administered price for a unit of service.

The Kennedy-Griffiths and the Kennedy-Mills plans differ in the way they deal with those related problems of induced costs and price competition. Kennedy-Griffiths would shift most payments to the national health program in order to remove *all* financial barriers to care. Under Kennedy-Mills, patients would share payment with the program up to a maximum of $1000 per family in out-of-pocket costs.

The theory supporting cost-sharing is this: Doctors and, to a lesser degree, patients will be encouraged to choose the most economical form of treatment—or no treatment at all—if patients must pay a portion of the cost out of pocket. More concretely, cost-sharing is meant to discourage unnecessary hospitalization, unnecessary elective surgery, frivolous visits to the doctor, and over-prescribing of medicines.

That theory may appear plausible. But there's no convincing research evidence that cost-sharing works or doesn't work in the manner prescribed by economic theory. Because of this uncertainty, CU urges that any national health insurance program at least eliminate cost-sharing for poor people and, in addition, eliminate any cost-sharing for preventive services (such as immunizations and regular check-ups) and for hospitalization. Furthermore, the program should conduct controlled experiments to test the effectiveness of

NATIONAL HEALTH INSURANCE COSTS AT A GLANCE



The chart above is derived from a report to Congress submitted by the Secretary of Health, Education, and Welfare last July. Although totals will probably change with inflation, relationships among plans are likely to remain unchanged, as is the share of costs within plans paid by individuals, private insurers, and Federal, state, and local governments. Note that the significant difference among plans is not the total cost, but who pays it—and how.

cost-sharing. If cost-sharing is shown to deter persons from seeking *needed* care, it should be eliminated.

THE PROBLEM OF ADMINISTRATION

The second major difference between the Kennedy-Mills and Kennedy-Griffiths plans is in administration. Kennedy-Mills would rely on private insurance companies to pay claims under overall Federal supervision. That's the way Medicare is run, and the example hardly inspires confidence.

Kennedy-Griffiths, by contrast, would put the private insurers out of business. Instead, there would be a new Federal bureaucracy to administer the program.

But there's little reason to cheer the prospect of total Federal administration, either. The Government, which supervises Medicare, must share blame with insurance companies for Medicare's uncontrolled costs and unresponsiveness to consumers. With the exception of Social Security, the experience is hardly better with other large-scale social programs run by the Government. Welfare medical programs, such as Medicaid, have become notorious for administrative insensitivity and red tape. "Perhaps the strongest argument for preserving a role for private insurance in the administration of national health insurance," says a study by the Health Law Project of the University of Pennsylvania, "is that a system operated by the Federal Government could be similarly inaccessible and unresponsive to consumer and public interests."

In addition, there would be mammoth institutional problems in establishing a new Government agency to operate a national health program in its entirety. Some 30,600 Government and insurance employes now administer Medicare. With all ages included in a national program, the new agency would require at least 70,000 employes. And it would take years for the agency to acquire the specialized staff needed for full, efficient operation. In addition, there's no evidence that such an agency would be more efficient than private insurers in handling claims.

CU, obviously, is not happy with the administrative choices presented by the Kennedy-Mills and Kennedy-Griffiths plans. We wish there were something better, but we don't know what it is.

A reasonable approach is to begin a national health insurance program that uses the strengths of the present private insurance system—identity, organizational structure, and buildings and staff throughout the country—but imposes stringent performance criteria on the insurers. An independent Government watchdog agency should monitor the companies. If they fail to meet specified goals for consumer representation and responsiveness, claims efficiency, and cost control, they should be phased out gradually in favor of total Government administration.

While there's reason to believe the new Congress will pass a national health insurance bill, there's reason to fear that the final compromise will fail to meet many of the stated consumer goals. Should you care to write on this subject, letters to Representatives should be addressed to the House Office Building, Washington, D.C. 20515. Those to Senators should be sent to the Senate Office Building, Washington, D.C. 20510.

Mascaras

Women use mascara to enhance the appearance of the eyes. So it was surprising to find that women choose a brand of mascara less for its appearance than for its freedom from irritation and its permanence.

This finding emerged when we questioned 300 women on their use of mascara. Apparently, they felt they could correct appearance defects as they applied the mascara, but that they couldn't tolerate smarting eyes and streaking lashes.

An examination of the product itself will help explain why the women answered as they did. In essence, mascara (from the Italian *maschera*, meaning mask) is a temporary eyelash paint. Like other paints, it consists of a solid pigment dispersed in a vehicle that is liquid enough for brushing. Most mascaras sold today are liquid, already thinned to the proper consistency. The older cake mascaras, which tend to be less expensive, require the user to add water before applying.

The fact that these paints are used so close to the eye places severe restrictions on their formulations. Mascara may not contain any irritating or possibly toxic pigments, binders, or solvents. (Laboratory tests done by a consultant on all our mascaras as received showed no biological contamination.) A mascara's composition also has to meet apparently conflicting needs: It should last as long as you want it to and yet be easy to remove. At the same time, of course, it should be easy to put on and it should look good while it's on.

CU considered all these factors when we rated the 62 mascaras covered in this report. Of that total, 24 are black, 24 are brown, and 14 are blue. (Blue is a less popular color than black and brown, and some of the 14 brands we chose for testing did not offer blue.) All but four are what is termed "automatic." An "automatic" mascara is simply a liquid mascara in a tube, with an applicator (usually a spiral brush) attached inside the tube's cap. Two black and two brown mascaras are of the cake type.

To evaluate the performance characteristics, we enlisted a panel of 136 women. Fifty used black mascara, 50 used brown, and 36 used blue. Each panelist received three unidentified mascaras to test and evaluate. They applied and wore each one for about a week. The panelists scored each mascara for various performance characteristics, which we grouped into four major Ratings judgments, as follows:

Eye irritation. Irritation may include itching, burning, soreness, and other similar symptoms. Two mascaras—the brown *Revlon Fabulash The Extra Length* and the blue *Lashbrite Lash Long*—were significantly more irritating to the eye area than the others. Two others were judged conspicuously *less* irritating than the others—the black *Estee Lauder Lustrous Roll-On* and the brown *Coty Perfect Lashes*. (There was no correlation, by the way, between those tests results

ATTACHMENT B

Who can afford a nursing home?

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RO77

Who can afford a nursing home?

This year, 2.3 million of the nation's elderly will be living in a nursing home. Three decades from now that number will nearly double. A year in a nursing home now costs on average $22,000 or more. By the year 2018, it will cost about $55,000 if inflation stays at recent moderate rates.

Who will pay the bill?

Medicaid, the Federal program that finances health services for the poor, paid half of the $38-billion that went into nursing-home care in 1986. Most people aren't poor when they enter a nursing home, but they become poor soon after.

The other half of the $38-billion came out of the pockets of nursing-home residents or of their children, who often find themselves squeezed between the financial needs of their own family and the burden of caring for aged parents.

Contrary to popular belief, Medicare, the Federal program that provides health care for the aged, pays only a tiny fraction of the cost of nursing-home care.

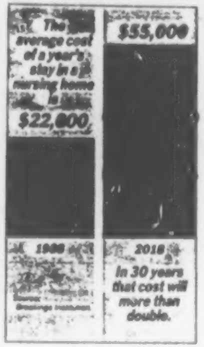
The Reagan Administration believes that the Federal government has no role to play in providing long-term care unless you're poor. The nonpoor, it tells us, should look to private insurance companies for protection against the potentially devastating financial consequences of a prolonged stay in a nursing home. As a result, long-term-care insurance policies, unknown until a few years ago, have proliferated. Currently, some 70 companies, ranging from familiar giants like Aetna and John Hancock to lesser-known firms like Reserve Life and Pilgrim Life, have entered the field. For this report, we analyzed 53 of their policies.

We'd like to report that private insurance policies can meet the increasingly urgent need for long-term-care coverage at a moderate cost. But many of the insurance policies we looked at were very expensive, severely limited in their coverage, or both. People who buy them at age 65 may have to pay as much as $100 a month for adequate coverage. People who try to shop for them will run into a crazy quilt of charges, waivers, and limitations that confuses even the insurance agents who sell the policies.

Defining the policy

Simply stated, long-term-care insurance pays a set amount each day for a specified period of time that a policyholder stays in what's called a "covered nursing facility." Unlike other kinds of health insurance, these policies usually don't reimburse the policyholder for fees actually charged. The fixed benefit is one major drawback of nearly all such policies. Should you buy a policy today and enter a nursing home 10 years from now, you may find that the benefit pays a much smaller part of the actual cost than you thought it would at the time you bought the policy. Only a few policies offer a rider that adjusts the benefit annually for inflation.

Furthermore, you'll find huge differences in dollar benefits, in definitions of covered nursing facilities, in the length of time benefits are paid, in limitations on coverage, and in eligibility for benefits. Those differences are spelled out in the Ratings on page 304.



Source: Brookings Institution

Type of facility covered

There are three types of long-term-care facility: skilled, intermediate, and custodial. A policy may or may not cover care in all three types, and different policies may define the three types of facility differently. In general, the definitions are the following:

Skilled nursing. Such care must be prescribed by a doctor, given by a skilled nurse, and be available for 24 hours a day. These facilities are licensed by the state, and daily medical records are kept on each patient.

Intermediate. In such facilities, care may require the skills of a nurse, but the level of care is somewhat less than that given in a skilled-care facility. For example, a nurse may be on hand only to give patients injections or to change their bandages. The facility may be licensed and may provide post-hospital and rehabilitative nursing care.

Custodial. Care here means helping a person with such routine activities as getting out of bed, walking, eating, and bathing. It may be given by people without professional skills or training, but some insurance policies may require that the facility be licensed.

The best policies pay benefits for all three kinds of care in all three types of facility. Buy less than the best, and you may discover that your insurance doesn't cover the type of care you require.

Note that policies can imply coverage where none exists. For example, a policy might provide coverage for all three *types* of care, but require that the care be given in only *one* type of facility, such as a nursing home that provides skilled care.

Custodial care is sometimes covered only if it is provided in a skilled- or intermediate-nursing facility. Some policies pay no benefits for custodial care, no matter where it's given. That's a major deficiency. Very few people need skilled care for long periods; much of the care in nursing homes is of the intermediate or custodial variety. Stroke victims, in particular, often require a long period of custodial care while recovering.

Qualifying for benefits

Most policies require beneficiaries to be hospitalized for at least three days before they enter a nursing home. And usually the nursing home must continue to provide care for the illness or condition that put the individual in the hospital.

Furthermore, the person must check into the nursing home within a certain period after checking out of the hospital. That period is usually 30 days, but it can be as short as 14 days or as long as 90 days. These rules can limit the usefulness of the insurance. Such debilitating conditions as arthritis and Alzheimer's disease usually do not require hospitalization. Only about 40 percent of all nursing-home patients check in after a hospital stay.

A few policies do not demand a hospital stay before paying benefits for long-term care. But the companies that issue them, including Blue Cross/Blue Shield and Metropolitan Life, do retain the power to decide who is eligible for benefits. Some companies, including MidAmerica and Continental Casualty, offer buyers a choice of policies with and without "prior-hospitalization" rules. Of course, the ones without these rules generally cost more.

We found nine policies free of either the prior-hospitalization rule or the company's veto of a policyholder's eligibility for nursing-home coverage.

Other restrictions may stand in the way of custodial care, which is potentially the longest-lasting and hence the most costly type of care. John Hancock's individual policy, for example, pays for care in a custodial facility only after 14 continuous days of skilled-nursing care. Aetna pays for a policyholder's first stay in a custodial facility only after a stay in either a skilled or an intermediate-care facility.

What's not covered?

No policy pays benefits for stays in rest homes or old-age homes. Nor do they pay for stays in mental hospitals or alcohol and drug rehabilitation centers. Most significantly, long-term-care policies tend to limit benefits for existing health problems and for Alzheimer's disease, the very reasons people might seek coverage in the first place.

Most companies limit coverage for "preexisting conditions"—those illnesses or diseases a buyer has when the policy is issued. The preexisting-conditions clause acts as a gatekeeper, turning away those who want to buy the coverage because they know they need it. If a company does not have a preexisting-conditions clause, it usually retains the power to decide who's eligible for benefits.

Most policies define a preexisting condition as any health problem experienced by the policyholder in the six months prior to buying the policy. But a number of policies count back one to three years.

If the insurance company sells a policy to a person with such a preexisting condition, it sets a waiting period before coverage for that condition can begin. These periods range from six months to two years. So if a heart condition lands someone in a nursing home three months after the policy was issued, the company won't start paying benefits immediately.

Virtually all the policies exclude care for mental and nervous disorders. Does that include Alzheimer's disease, a debilitating condition that's diagnosed in about half of all nursing-home patients?

Although Alzheimer's is not specifically excluded, about half the policies we looked at said something like "we won't pay for confinements due to mental illnesses except those with demonstrable organic disease." Alzheimer's disease is a degenerative brain disease with symptoms that mimic those of mental illness. It's considered an organic disease and therefore would seem to be covered. But is it a *demonstrable* organic disease? Only a biopsy or an autopsy can confirm a diagnosis of Alzheimer's disease.

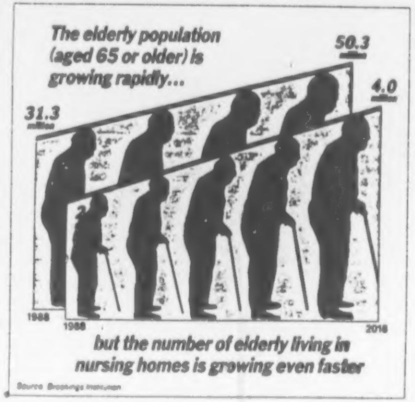
In our opinion, the vague policy language gives insurance companies too great an opportunity to contest a claim on the grounds that Alzheimer's disease has not been demonstrated. A company suddenly flooded with claims from policyholders with Alzheimer's disease might rely on that language as a basis for denying nursing-home coverage.

Other policies clearly state that Alzheimer's disease is covered. But here, again, there's a catch. Many of these policies also impose the prior-hospitalization rule. Most Alzheimer's patients, as we've noted, do not require hospitalization before they enter a nursing home.

When we asked an Aetna salesman about this, he replied: "To tell you the honest-to-goodness truth, if a doctor didn't find some way to get you into a hospital, then you're in trouble."

How large a benefit?

Daily benefits range from $25 to $100. Some policies offer a choice of benefit amounts. Obviously, it makes sense to pick a policy with benefits that closely match local nursing-home costs. A policy



Source: Brookings Institution

paying $40 a day when the local nursing home costs $140 isn't much help. A call to two or three homes will help to establish a reasonable range of daily charges. Nationally, the average cost of a nursing home is $60 a day.

Sometimes insurance companies pay smaller benefits for custodial care than for skilled and intermediate care. The Gerber Life policy, for instance, pays a $75 benefit for skilled-nursing care, a $50 benefit for intermediate care, but only $25 if a policyholder needs custodial care.

When do benefits begin?

Policyholders can often decide when they want their coverage to start—as soon as they enter a nursing home, 20 days later, or even 100 days later. The longer this "waiting period" (sometimes called an elimination period), the cheaper the policy.

How long do benefits last?

The best policies pay benefits for an unlimited number of days for each stay in a nursing home and an unlimited number of days for all nursing-home stays. Those stays in a nursing home are sometimes called "periods of confinement" or "benefit periods."

Other policies pay benefits for a specific number of days, ranging from 730 (two years) to 3650 (10 years) for one stay, and from 730 days (two years) to 2555 (7 years) for all nursing-home stays. A few policies don't limit the number of days they'll pay benefits. They set dollar maximums instead.

In order to receive benefits for a repeat stay in a nursing home, the policyholder must usually have been out of a nursing home for at least 180 days. And when he or she returns, the waiting period starts all over again, so coverage doesn't begin immediately. Waiting periods for preexisting conditions don't begin again, however.

Sometimes a policy will have a shorter benefit period for intermediate or custodial care than for skilled-nursing care. This could be a severe limitation, since nursing-home patients require skilled care less often than intermediate or custodial care. Nearly 40 percent of all nursing-home patients stay longer than six months. Chances are good that those longer-staying patients needed intermediate or custodial care, not skilled care.

What's in a good policy?

Features	*Recommended*	*Your policy*
Daily nursing-home benefit	$80.00	$
Waiting period	20 days	
Maximum benefit period for one stay	4 years	
Maximum benefit period for all stays	Unlimited	
Does it pay full benefits in:		
Skilled-nursing facility?	Yes	
Intermediate facility?	Yes	
Custodial facility?	Yes	
(If not, what does it pay?)		
If it has a prior-hospitalization rule, does coverage begin within 30 days after a hospital stay of at least 3 days?	Yes	
Does it pay home-care benefits?	Yes	
Does it pay these without requiring nursing-home care, or a hospital stay?	Yes	
Does it have waiver of premium?	Yes	
Is it guaranteed renewable for life?	Yes	
Is Alzheimer's disease covered by specific policy language?	Yes	
Does the premium stay level for life?	Yes	
What is the Best's rating of the company?	A or A +	
No premium is recommended; premiums vary with the age of the policyholder:	—	$

Are policies renewable?

Many policies are "guaranteed renewable," a desirable feature that insurance companies like to highlight in their sales literature. The company must renew coverage each time the policyholder pays the premium.

Beware of policies that are only "conditionally renewable." The insurer can cancel the policy provided it also cancels all other similar policies in a state. That could happen if an insurance company discovers it is losing money on this relatively new type of coverage.

A number of policies are written for groups such as the American Association of Retired Persons (AARP), or even for a fictitious group set up by the insurance company for marketing and regulatory purposes. The group holds the master contract and issues certificates to individual policyholders. The master contract for the group can be canceled, but policyholders are often able to continue the same coverage on their own.

What else to look for?

Here are other features we looked for in a policy:

Home care. More than half the policies in our study paid benefits for care at home. These benefits are usually offered as part of the basic policy coverage, but sometimes they are offered as a separate policy or as a rider at an additional premium. Home care typically covers convalescent care, homemaker or companion services, and occasionally even skilled-nursing care. A few policies define home care broadly enough to include care in hospices and adult day-care centers.

Typically, the home-care benefit is one half the daily benefit paid for skilled nursing or intermediate care, but that's where the similarity among policies ends. There's wide variation in eligibility for home-care benefits and in when those benefits begin and end.

Policies that require previous nursing home or hospital confinement would usually pay for home care only if it starts within 14 days after leaving the nursing home or hospital. Policies that do not have such a requirement would generally start paying as soon as the regular waiting period has ended.

Continued on page 6

Pitching the policies

It has never been easy to understand insurance policies. It's even tougher when the agents selling them don't understand what they're selling. And when the policy sold is brand-new, it takes a miracle to avoid misunderstanding, duplication of coverage, or even inadequate coverage.

A CONSUMER REPORTS reporter listened to sales pitches given by six insurance agents in New York and Virginia. Two agents represented Aetna; the others represented Union Bankers, Bankers Life and Casualty, Gerber Life, and Mutual of Omaha. Our reporter witnessed no miracles.

She found confusing presentations from agents who were either ignorant of the provisions in their policies or who deliberately misstated them. An Aetna agent in Virginia admitted, "I've never had to explain this to someone." Some agents were remarkably low key, acting as if they didn't want to sell the policy.

Alzheimer's confusion

About half of all nursing-home patients suffer from Alzheimer's and related diseases, so shoppers would want to know whether a policy provided coverage for such illnesses. They wouldn't have found out listening to these agents or reading their sales brochures. The agents' confusion may well reflect their company's indecision over whether to provide such coverage.

The Aetna agent in Virginia allowed that "it was questionable" whether his policy covered the disease, but said the company was "still looking at it." He added, "It's a mental disease, and they're not sure."

No wonder he was confused. The sales brochure sent by Aetna said Alzheimer's was covered, but the actual language in the policy was less specific. It said that the policy did not cover confinements for mental disease or disorders without demonstrable organic disease. As we point out on page 3, that language may or may not mean the disease is covered.

The Union Bankers agent said Alzheimer's was covered, but the brochure he left noted that the policy didn't cover nursing-home stays for "mental illness or nervous disorders." Did that mean Alzheimer's is covered? Our reporter could only guess.

What's covered?

Coverage is the guts of a long-term-care policy, but agents were of no help defining the coverage or discussing the policy limitations. Here's how the Aetna agent in New York handled these questions:

What about intermediate-care coverage? The agent fumbled for his sales brochure and replied: "They define it here somewhere." What about skilled nursing care? "On this plan, you don't have to worry about the definition," he assured us.

As for limitations on coverage, he said there were none. "Once you have this policy, you're covered for everything." Everything? The policy specifically says it does not provide benefits for six months if a nursing-home stay results from a preexisting condition.

A competitor also had trouble explaining coverage. The agent from Bankers Life and Casualty said that intermediate care was the same thing as "convalescent care" and that skilled care meant that "they do a little more medical than the others."

When asked whether any prior hospitalization is required before skilled-nursing benefits could be paid, the agent for Mutual of Omaha said: "I don't think so. I've never seen where you have to be hospitalized first." He didn't look very far. That's just what his company's sales brochure said.

What Medicare pays

Many people think that Medicare covers nursing-home stays (see box page 14). Actually, it pays for skilled nursing-home care in Medicare-approved facilities for only 20 days and then all but $67.50 per day for the next 80 days. After 100 days, Medicare pays nothing.

Here's what the agents said:

The Gerber Life salesman said that 70 percent of all applicants for Medicare benefits were turned down "because Medicare doesn't have funds for skilled care." But when Medicare does accept an individual, he said, "after 100 days, they wash their hands of you."

The Bankers Life and Casualty agent said that Medicare paid for 100 percent of home health-care costs. "It's a wonderful benefit," he said, declaring that Medicare pays "for girls to come in" and "help do your hair."

The agent had let his imagination run away with him. Medicare's home-care benefit is very limited, and it certainly doesn't pay for beautician services. It pays only for part-time, intermittent skilled care and for physical or speech therapy. The provider must participate in Medicare.

What about rate hikes?

It wasn't always easy to get a straight answer about whether premiums could go up or policies could be renewed.

The Bankers Life and Casualty agent incorrectly said the premiums would never increase, wrongly labeling this policy feature as "guaranteed renewable." The policy and the sales brochure say that the company can raise premiums if it raises them for all policies like the one the agent was selling.

The Aetna agent in Virginia also assured our reporter that the premiums would not increase. "Once these premiums are set, you'll be paying them forever." He even double-checked his sales manual. "No, they shouldn't go up," he repeated. The sales literature he gave to our reporter didn't say one way or the other, but Aetna's policy is similar to the one from Bankers Life and Casualty. Both companies can raise rates for everyone who owns the same policy in the state.

The Mutual of Omaha salesman was thoroughly confused. His policy is not guaranteed renewable, but he replied, "It is and it isn't. If the state does not permit the company to renew, then we have to pull the policy." While that statement is true enough, it has nothing to do with the renewability feature of his policy.

Mutual of Omaha's sales brochure revealed that the company could refuse to renew a policy, if it refuses to renew them for all those who own that particular policy in the same geographic area of the policyholder's state.

Which one is best?

Naturally, each agent declared his policy the best. The feature they all cited as evidence was the length of time benefits would be paid—unquestionably important, but not necessarily the only measure of superiority.

The Gerber salesman touted his policy as the best because he said it paid benefits for "eight continuous years." And he knocked the American Progressive policy. But as you can see from the Ratings, the Gerber policy was hardly the best, ranking near the bottom. The American Progressive policy ranked close to the top.

What's best is a combination of features. To help you figure out which policy is best, ask for answers to all the questions listed in the box on page 4.

If you get answers that are vague or that contradict the sales literature, ask for a specimen policy. The policy will tell you exactly what's covered and what's not, setting out all the limitations you need to know about.

An agent might be reluctant to give you a specimen policy, however. When our reporter asked the Mutual of Omaha salesman for one, he refused to supply it. If that happens, write to the company. If a company doesn't give you what you need, go to one that does

Policies usually pay home-care benefits until the regular benefit period maximum has run out. But we found policies that paid home-care benefits for other periods: 30 days, 90 days, one year, two years, or even three years.

Inflation adjustments. The greatest danger facing policyholders is the lack of inflation protection. The $40, $75, or even $100 daily benefit paid by policies today may be woefully inadequate if you need nursing-home care 5 or 10 years from now.

Only one company, Great Republic, sells a policy with built-in inflation protection. The benefit automatically increases by 5 percent each year for as long as a policyholder hangs on to the policy.

Other companies allow policyholders to buy a rider that automatically raises benefits by some amount each year, usually 5 percent. These automatic increases usually stop after 10 years. The riders generally add between 15 and 40 percent to the premium, depending on the coverage.

A few policies pay benefits based on the actual nursing-home charges. If these charges go up, then the benefits will rise as well.

Waiver of premium. Many insurers relieve policyholders of paying further premiums once they've been in a nursing home for a period of time, usually 90 days. This feature is often part of the basic policy, but occasionally policyholders will have to pay extra for it.

Assistance in finding care. A few sellers employ care coordinators who help people find facilities that are covered by their policies. Other companies have toll-free telephone numbers that policyholders or their families can call to find out about nursing homes in their areas.

Will the price go up?

As with life insurance, the older you are when you buy the policy, the more expensive it is. A 75-year-old buying Great Republic's long-term-care policy will pay $3143 a year. A 55-year-old can buy the same policy for $611 a year.

In most cases, the premiums remain "level"—they don't increase after someone buys the policy. (Premiums that do increase annually or every few years as the policyholder grows older make a policy far less desirable.)

But a level premium is not necessarily as level as it looks. A company can increase a so-called level premium on your policy provided it also increases the premium for everyone else in your state who bought the same policy.

One CONSUMER REPORTS reader wrote us about his experience with a policy from Massachusetts Indemnity and Life. The

Continued on page 10

Guide to the Ratings

Listed in order of estimated overall quality. Within red rules, plans were judged approximately equal in quality.

① **Premium.** Premium paid at age 65, expressed as a monthly amount for the purposes of the Ratings.

② **Daily benefit.** The amount of money a policy pays for each day spent in a covered care facility.

③ **Waiting period.** The number of days a policyholder must be in a facility before coverage actually begins.

④ **Each period.** The number of days a policy pays for one stay in a nursing home. Some policies have dollar maximums instead.

⑤ **All periods.** The number of days a policy pays for all nursing-home stays.

⑥ **Skilled.** Policy pays benefits for care in a skilled-nursing facility.

⑦ **Intermediate.** Policy pays benefits for care in an intermediate-nursing facility.

⑧ **Custodial.** Policy pays benefits for care in a custodial-nursing facility. Care is usually limited to helping people perform routine activities.

⑨ **Home care.** Policy pays benefits for care at home.

⑩ **No prior hospitalization.** Most policies require a hospital stay of at least three days before entering a nursing home. Policyholder must also enter nursing home within 30 days of hospital discharge. A — indicates the policy has a prior-hospitalization rule. Variations of this rule are listed under advantages and disadvantages.

⑪ **Alzheimer's coverage.** The policy language specifies that Alzheimer's disease is covered.

⑫ **Inflation adjustment.** An optional rider or other arrangement which increases benefits by a set percentage each year for a certain number of years.

⑬ **Preexisting conditions.** Policy covers care for preexisting conditions—ailments or illnesses a policyholder has at the time a policy is issued.

⑭ **Level premiums.** A premium that doesn't increase with the age of a policyholder is highly desirable.

⑮ **Guaranteed renewable.** Company will always renew coverage each time the premium is paid. Without this protection, a company can usually cancel the policy if it cancels all other policies of that type in a state.

⑯ **Waiver of premium.** Feature allows policyholders to stop paying premiums once they've been in a nursing home for a certain period, usually 90 days.

⑰ **Rejection rate.** The percentage of applicants rejected by a company. A — indicates company provided no information.

⑱ **Substandard risks.** Someone who has health problems can buy insurance with a higher premium, **P**, or a waiver, **W**, that excludes coverage for those problems. Waivers are undesirable.

Ratings

Nursing-home insurance

Company name	① Premium	② Daily benefit	③ Waiting period	Maximum benefit ④ Each period	 ⑤ All periods	Type of facility ⑥ Skilled	 ⑦ Intermediate	 ⑧ Custodial	⑨ Home care	⑩ No prior hospitalization	⑪ Alzheimer's coverage	⑫ Inflation adjustment	⑬ Preexisting conditions	⑭ Level premiums	⑮ Guaranteed renewable	⑯ Waiver of premium	⑰ Rejection rate	⑱ Substandard risks	Advantages	Disadvantages
Great Republic with Skilled Care at Home Rider 206-285-1422	$ [illegible]	$ 80	20	unlimited	unlimited	[18]	✓	✓	✓	—	—	✓	—	✓	✓	✓	10%	—	B,E	I
John Hancock Mutual Life Protectcare - individual 617-421-6000	76.52 [1]	100	20	2190	2190	✓	[14]	[17]	✓	✓	✓	✓	—	✓	✓	✓	20-25	—	A,C	—
American Progressive Life & Health 800-243-9214	57.24	80	20	1095	1825	✓	✓	[18]	✓		—	—	—	✓	✓	✓	5	—	—	—
Bankers Life and Casualty with Home Health Care Benefit Rider 312-777-7000	53.54	50	20	1095	unlimited	✓	✓	✓	✓	—	✓	✓	—	✓	✓	✓	10	—	—	—
Bankers Multiple Line with Home Health Care Benefit Rider 312-777-7000	53.54	50	20	1095	unlimited	✓	✓	✓	✓	—	✓	✓	—	✓	✓	✓	10	—	—	—
Certified Life with Home Health Care Benefit Rider 312-777-7000	53.54	50	20	1095	unlimited	✓	✓	✓	✓	—	✓	✓	—	✓	✓	✓	10	—	—	—
Union Bankers with Home Health Care Benefit Rider 312-777-7000	53.54	50	20	1095	unlimited	✓	✓	✓	✓	—	✓	✓	—	✓	✓	✓	3	—	—	—
Equitable Life and Casualty 800-453-3245	52.56	60	30	3650	$250,000	✓	✓	[18]	✓	—	—	—	—	✓	✓	✓	7	—	—	I
Life Insurance Co. of Connecticut 800-645-9876	68.04	80	20	1095	1825	✓	✓	[18]	✓	—	—	—	—	✓	✓	✓	5	—	—	I
Metropolitan Life Group Policy for Williamsburg Landing 212-578-2211	95.00 [2]	48 [4]	60	unlimited	unlimited	✓	✓	✓	✓	✓	✓	✓	—	✓	—	—	10	F	D,F	b,e,h
Farwest American Assurance Co. 503-224-7740	50.67	80	20	1460	2190	✓	✓	[18]	✓	✓	✓	✓	—	✓	✓	✓	12	—	A	—
Bankers Life and Casualty without Home Health Care Benefit Rider 312-777-7000	36.30	50	20	1095	unlimited	✓	✓	✓	—	—	✓	✓	—	✓	✓	✓	10	—	—	—
Bankers Multiple Line without Home Health Care Benefit Rider 312-777-7000	36.30	50	20	1095	unlimited	✓	✓	✓	—	—	✓	✓	—	✓	✓	✓	10	—	—	—

[1] Represents one-twelfth of company's annual premium. Monthly premium, if available, would probably be higher.

[2] Composite rate means the company charges the same premium at all ages.

[3] Represents weekly premium.

[4] Benefit paid for one person; policy pays $60 for first spouse of a couple living together.

[5] Pays 80 percent of actual charge with maximum policy payment of $80 a day.

[6] Pays 100 percent of actual cost.

[7] Pays for "usual and customary" charges up to a maximum of $50.

[8] Pays 100 percent of "eligible" charges up to a maximum of $75.

[9] Pays this for skilled care; pays $50 for intermediate care and $25 for custodial care.

[10] Pays 75 percent of charges based on negotiated rates with participating provider.

[11] Daily equivalent of company's $2000 a month benefit.

[12] Pays half benefits for first 50 days, but waiting period does not apply.

[13] Pays for custodial care only.

[14] Depends on company's interpretation.

[15] Shorter benefit period.

[16] Reduced daily benefit.

[17] Only after 14 days skilled-nursing care.

[18] Benefits paid only after pre-confinement in skilled or intermediate facility; benefits are reduced and paid over a shorter period.

Key to Advantages

- A - No prior hospitalization required; company does not arbitrarily decide whether policyholder requires nursing-home care.
- B - Built-in inflation adjustment.
- C - Toll-free number available to policyholders needing help with nursing-home selection.
- D - Care coordinator available to help policyholders find nursing homes.
- E - Intermediate or custodial care must follow either hospital confinement of two days or skilled confinement of 10 days.
- F - Benefit represents 100 percent of incremental cost for retirement-home resident.
- G - Product operates according to HMO service-provided principles.
- H - Will verify that institution complies with group certificate language as a covered facility.
- I - Must check into nursing home within 90 days of discharge from hospital.
- J - Company has large variety of home-care coverages available in separate policy or rider.

Key to Disadvantages

- a - Policyholder must check into nursing home within 14 days of discharge from a hospital—a very short time for decisions.
- b - Company arbitrarily decides whether policyholder requires nursing-home care.
- c - Has premiums that go up annually as policyholder gets older.
- d - Has premiums that go up every few years.
- e - Conditionally renewable, or group insurance contract.
- f - Must remain in retirement community group to keep coverage.
- g - Pays for custodial care that takes place in a skilled or intermediate facility.
- h - Intermediate facilities and custodial facilities (Personal Care Homes) must be on site and owned by retirement community.
- i - Pays only if the facility qualifies, irrespective of level of care.
- j - Pays for intermediate or custodial care that takes place only in a skilled facility.
- k - Pays for skilled, intermediate, or custodial nursing care only in a skilled facility.
- l - Company has Best's rating of B or lower, or is not assigned by Best's.

Ratings of Nursing-home insurance

Continued

Company name	① Premium	② Daily benefit	③ Waiting period	Maximum benefit		Type of facility			⑨ Home care	⑩ No prior hospitalization	⑪ Alzheimer's coverage	⑫ Inflation adjustment	⑬ Preexisting conditions	⑭ Level premiums	⑮ Guaranteed renewable	⑯ Waiver of premium	⑰ Rejection Rate	⑱ Substandard	Advantages	Disadvantages
				④ Each period	⑤ All periods	⑥ Skilled	⑦ Intermediate	⑧ Custodial												
Certified Life without Home Health Care Benefit Rider 312-777-7000	$ 36.30	$50	20	1095	unlimited	✓	✓	✓	—	—	✓	✓	—	✓	✓	✓	10%	—	—	—
Union Bankers without Home Health Care Benefit Rider 312-777-7000	36.30	50	20	1095	unlimited	✓	✓	✓	—	—	✓	✓	—	✓	✓	✓	3	—	—	—
John Hancock Mutual Life Flex Plan 88 - Group Policy 617-421-6000	16.11 [3]	[5]	90	1460	1460	✓	[14]	✓	✓	✓	✓	✓	—	✓	✓	✓	5-10	—	D	b
Group Health Cooperative of Puget Sound Security Care Agreement of Metropolitan Life 212-578-2211	80.00	[6]	30	1460	1460	✓	✓	✓	✓	✓	✓	✓	✓	✓	—	—	20-30	—	D,G	b,e
World Life & Health of Pennsylvania 800-521-1200	53.75 [1]	50	0	730	unlimited	✓	✓	✓	✓	—	—	—	—	✓	✓	✓	3	P,W	C	l
Transport Life 817-390-8000	89.56	60	0	1460	$204,400	✓	✓	✓	✓	—	—	—	—	✓	—	✓	3-5	—	H	e
AMEX Life 415-492-7000	33.00 [1]	55	20	1460	1460	✓	✓	[12]	✓	—	✓	✓	—	✓	✓	✓	10-20	—	C,I	—
Aetna Life and Annuity Long Term Care Plan 203-273-0123	33.02	50	20	1460	1460	✓	✓	[13]	✓	—	—	✓		✓	✓	✓	10	—	C	—
Reserve Life 214-670-0700	37.32	60	100	1095	1095	✓	✓	[13]	✓	—	—	—	—	✓	✓	✓	5	—	—	—
Acceleration Life 614-764-7000	83.16	80	100	1825	1825	✓	✓	✓	✓	—	—	—	—	✓	—	✓	3	W	—	e
MidAmerica Mutual Life with Prior Hospitalization 612-331-6370	67.20	60	20	$60,000	$60,000	✓	✓	✓	✓	—	✓	—	—	—	✓	✓	—	—	—	c
Continental Casualty with Home Health Care Rider 312-822-5000	43.25	60	15	1825	2555	✓	✓	—	✓	—	—	✓	—	✓	✓	✓	15	P	—	g
Harvest Life 616-968-7200	44.22	50	20	1095	1825	✓	✓	✓	✓	—	—	—	—	✓	—	✓	1	—	—	e
Mutual Protective 402-391-6900	43.95 [1]	60	20	1095	1460	✓	✓	—	✓	✓	✓	—	—	✓	✓	✓	17	P	A,C	g
Continental Casualty without Home Health Care Rider 312-822-5000	38.40	60	15	1825	2555	✓	✓	—	—	—	—	✓	—	✓	✓	✓	15	P	—	g
MidAmerica Mutual Life without Prior Hospitalization 612-331-6370	78.60	60	20	$100,000	$100,000	✓	✓	✓	✓	✓	✓	—	—	—	✓	✓	—	—	A	c
Prudential, American Association of Retired Persons (available April, 1988) 800-523-5800	55.00	50	90	1095	1095	✓	✓	✓	✓	✓	✓	—	—	✓	✓	✓	—	—	A,C	—
Federal Home Life 800-253-0056	42.50 [1]	50 [7]	20	1095	1825	✓	✓	✓	✓	—	—	—	—	✓	—	✓	1	—	—	e
Blue Cross of Washington and Alaska 800-231-0610	69.58 [1]	75 [8]	20	2190	2190	✓	✓	✓	✓	✓	—	—	✓	✓	✓	✓	20-22	—	D	b
AIG Life Group Long Term Care Certificate with Extended Home Care Rider 302-594-2000	68.20	60	20	1825	1825	✓	—	—	✓	—	✓	—	—	✓	✓	✓	20	—	D	i
American Travellers Life without Supplemental Home Health Care Policy 215-343-1000	24.30	50	0	730	730	✓	[9]	[9]	—	—	—	—	—	✓	✓	—	2-4	P	J	e,l
NN Investors Life with Home Health Care Rider 800-330-0257	37.80	60	20	1000	1500	✓	✓	—	✓	—	—	—	—	✓	✓	✓	13	P	C	g
Columbia Life 717-784-2716	42.50	50	20	1460	1460	✓	[15]	[15]	—	✓	—	—	✓	✓	✓	✓	2	P,W	A	l
Travelers Long Term Care Plan Trust 203-277-0111	66.75	50	90	$75,000	$75,000	✓	✓	[14]	✓	✓	✓	—	—	✓	✓	✓	—	—	A,C	g
American Republic with Home Health Care Benefit 515-245-2000	66.42	60	60	$90,000	$90,000	✓	✓	—	✓	✓	✓	—	—	✓	✓	✓	15	—	A,C	g
NN Investors Life without Home Health Care Rider 800-330-0257	29.16	60	20	1000	1500	✓	✓	—	—	—	—	—	—	✓	✓	✓	13	P	C	c
Penn Treaty Life with Supplemental Coverage for Home Health Care 800-222-3469	75.19	50	0	730	730	✓	✓	✓	✓	—	—	—	—	✓	✓	✓	10	P,W	—	e,l
Prudential, American Association of Retired Persons (Previous Plan) 800-523-5800	48.75	50	90	1095	1095	✓	✓	✓	✓	✓	—	—	—	✓	—	✓	8	—	C	e
American Republic without Home Health Care Benefit 515-245-2000	58.44	60	60	$90,000	$90,000	✓	✓	—	—	✓	✓	—	—	✓	✓	✓	15	—	A,C	g
Colonial Penn Life 800-523-4000	55.15 [1]	60	20	1095	unlimited	✓	✓	—	✓	—	—	—	—	✓	✓	✓	2	—	—	g
Gerber Life 914-761-4404	39.59	75 [8]	100	1825	$187,500	✓	[12] [16]	[13] [16]	—	—	—	—	—	✓	✓	—	—	—	—	a
Finger Lakes Long Term Care, Subsidiary of Blue Cross and Blue Shield of Rochester 716-454-1700	102.56	[10]	100	1825	1825	[17]	[17]	[17]	✓	✓	✓	✓	—	✓	✓	✓	30	—	D	b
American Sun Life with Home Convalescent Policy 305-447-3111	56.81	60	0	1095	unlimited	✓	—	—	✓	—	—	—	—	—	—	✓	—	—	—	d,e,k,l
United General Life with Home Convalescent Care Coverage 813-544-8881	39.83 [1]	60	0	730	unlimited	✓	—	—	✓	—	—	—	—	—	—	✓	10 or less	—	—	j,c,l
Pilgrim Life Three Diamond Plan with Home Private Duty Nursing Benefit of $100 per day 215-534-8000	65.19	67 [11]	0	730	730	✓	✓	✓	✓	—	—	—	—	✓	—	—	1	P	—	e,l
Penn Treaty Life without Supplemental Insurance Coverage for Home Health Care 800-222-3469	52.24	50	0	730	730	✓	✓	✓	—	—	—	—	—	✓	✓	✓	10	P,W	—	a,l
American Sun Life without Home Convalescent Policy 305-447-3111	31.32	60	0	1095	unlimited	✓	—	—	—	—	—	—	—	—	—	✓	—	—	—	d,e,k,l
Pilgrim Life Three Diamond Plan without at Home Private Duty Nursing 215-534-8000	52.20	67 [11]	0	730	730	✓	✓	✓	—	—	—	—	—	✓	—	—	1	P	—	e,l
Life and Health of America 215-567-1246	100.00	40	20	730	730	✓	✓	✓	—	—	—	—	—	✓	✓	—	2	—	—	a
United General Life without Home Convalescent Care Coverage 813-544-8881	28.08 [1]	60	0	730	unlimited	✓	—	—	—	—	—	—	—	—	—	✓	10 or less	—	—	j,c,l

Key to Advantages

A – No prior hospitalization required; company does not arbitrarily decide whether policyholder requires nursing-home care.
B – Built-in inflation adjustment.
C – Toll-free number available to policyholders needing help with nursing-home selection.
D – Care coordinator available to help policyholders find nursing homes.
E – Intermediate or custodial care must follow either hospital confinement of two days or skilled confinement of 10 days.
F – Benefit represents 100 percent of incremental cost for retirement-home resident.
G – Product operates according to HMO service-provided principles.
H – Will verify that institution complies with group certificate language as a covered facility.
I – Must check into nursing home within 60 days of discharge from hospital.
J – Company has large variety of home-care coverages available in separate policy or rider.

Key to Disadvantages

a – Policyholder must check into nursing home within 14 days of discharge from a hospital—a very short time for decisions.
b – Company arbitrarily decides whether policyholder requires nursing-home care.
c – Has premiums that go up annually as policyholder gets older.
d – Has premiums that go up every few years.
e – Conditionally renewable, or group insurance contract.
f – Must remain in retirement community group to keep coverage.
g – Pays for custodial care that takes place in a skilled or intermediate facility.
h – Intermediate facilities and custodial facilities (Personal Care Homes) must be on site and owned by retirement community.
i – Pays only if the facility qualifies, irrespective of level of care.
j – Pays for intermediate or custodial care that takes place only in a skilled facility.
k – Pays for skilled, intermediate, or custodial nursing care only in a skilled facility.
l – Company has Best's rating of B or lower, or is not assigned by Best's.

[1] *Represents one-twelfth of company's annual premium. Monthly premium, if available, would probably be higher.*

[2] *Composite rate means the company charges the same premium at all ages.*

[3] *Represents weekly premium.*

[4] *Benefit paid for one person; policy pays $80 for first spouse of a couple living together.*

[5] *Pays 80 percent of actual charge with maximum policy payment of $80 a day.*

[6] *Pays 100 percent of actual cost.*

[7] *Pays for "usual and customary" charges up to a maximum of $80.*

[8] *Pays 100 percent of "eligible" charges up to a maximum of $75.*

[9] *Pays this for skilled care, pays $50 for intermediate care and $25 for custodial care.*

[10] *Pays 75 percent of charges based on negotiated rates with participating provider.*

[11] *Daily equivalent of company's $2000 a month benefit.*

[12] *Pays half benefits for first 50 days, but waiting period does not apply.*

[13] *Pays for custodial care only.*

[14] *Depends on company's interpretation.*

[15] *Shorter benefit period.*

[16] *Reduced daily benefit.*

[17] *Only after 14 days skilled-nursing care.*

[18] *Benefits paid only after pre-confinement in skilled or intermediate facility; benefits are reduced and paid over a shorter period.*

Insurance regulators look the other way

Every state has a department of insurance that's supposed to protect consumers by regulating the insurance policies sold in that state and by supervising the activities of insurance companies. But with few exceptions, regulators are reluctant to look too closely at long-term-care insurance policies, for fear that insurance companies will refuse to provide any coverage at all rather than tailor coverage to meet stern regulatory requirements.

"We are treating long-term care differently than other lines of insurance," says Fred Bodner, chief of the New York Insurance Department's Health and Life Policy Bureau. "We're not going to approve a policy if it's a rip-off, but we're not going to turn it down if it isn't wonderful."

The National Association of Insurance Commissioners (NAIC), which writes model laws for all states to adopt, has written one for long-term-care policies. So far, 11 states have adopted this model, and companies selling policies in these states must comply with its provisions.

States in which insurance policies must meet the NAIC standards are: Arizona, Hawaii, Indiana, Iowa, Kansas, Nebraska, North Carolina, North Dakota, Oklahoma, Oregon, and Virginia. Wyoming and Georgia were about to adopt the model law as we went to press.

The model has some good rules. Waivers denying coverage for specified health conditions are prohibited, and companies cannot offer substantially greater benefits for skilled nursing care than for custodial and intermediate care. Policies must also be guaranteed renewable, but state insurance commissioners may allow cancellation in limited circumstances.

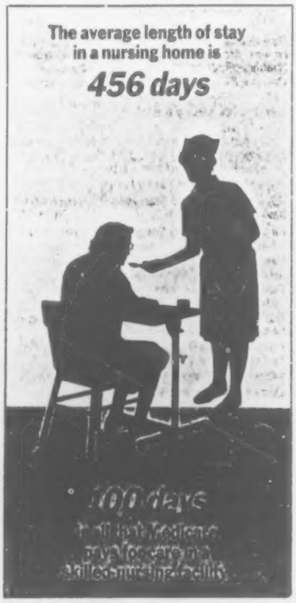
The NAIC model permits other features we consider undesirable: Companies can require a hospital stay before providing benefits for nursing-home care, and can require that a policyholder receive skilled care before qualifying for intermediate, custodial, or home-care benefits. Although the NAIC model prohibits companies from excluding coverage for Alzheimer's disease, it doesn't require policies to specifically spell out that the disease is covered.

Not addressed by the NAIC model law is the need for standard language for long-term-care policies, much like the standard language found in a homeowners policy. Without it, consumers will be forced to rely on confused agents and equally confusing sales brochures.

When CU asked all 50 state-insurance commissioners what complaints had developed from the sale of long-term-care insurance, we learned that consumers complained most often about the unanticipated limitations on the coverage provided by their policies. Consumers believed that their policies covered them for a particular kind of care when, in fact, no such coverage existed.

Members of the NAIC advisory committee that wrote the model law considered requiring companies selling long-term-care policies to include the telephone number of the state-insurance department on forms given to policyholders who are thinking about replacing their policies. That way consumers could call their state regulators if they couldn't decipher a policy. But the committee scrapped the idea when insurance companies argued it would not provide a substantial benefit to consumers.

If insurance regulators don't help buyers of long-term-care policies, who will?



premium for his long-term-care policy had jumped a whopping 150 percent, from $180 to $450, in a single year.

Long-term-care policies don't have much of a history. As a result, insurance-company actuaries may be unable to predict nursing-home use or future costs accurately. Some insurance companies may be pricing their policies too low to cover the promised benefits in the future.

Are you insurable?

Someone who's sick and ready to check into a nursing home can't buy a policy from most companies. Many insurance companies have instructed their agents to weed out "undesirables" before applications reach the home office. If an agent sees that a person can't get out of bed alone or learns that a person has osteoporosis or Alzheimer's disease, the agent won't even deliver a sales pitch. An Aetna agent in Virginia told our reporter that she had to come to his office to hear the sales presentation, probably to see whether she could actually walk.

People who are turned down for life or health insurance might nevertheless be good risks for long-term care insurance. "Someone with terminal cancer may be a better risk than someone with mild arthritis," says Karl Michaelson, director of health-products underwriting for Aetna. "We do not like to insure people who need aids in getting around—like walkers, canes, and oxygen."

Some companies are choosier than others. Rejection rates vary from 1 percent for Harvest Life, Pilgrim Life, and Federal Home Life to 30 percent for Finger Lakes Blue Cross/Blue Shield.

Many companies offer coverage to people with less-than-perfect health by applying "waivers," which exclude coverage for certain conditions. But buying a policy with a waiver for an illness that's likely to land you in a nursing home is a waste of money.

Instead of waivers, some companies offer coverage at higher rates to people who have health problems. Depending on the severity of the illness or condition, a "substandard risk" could pay as much as 100 percent more than a person whose health qualified him or her for the company's standard rate.

Evaluating the policies

We requested data from 81 insurance companies that sell long-term-care policies or that will start to offer them in the near future. Some told us they were withdrawing their policies and wouldn't have new ones ready in time for us to evaluate. Several companies, including Mutual of Omaha, United American, Combined American Life Insurance Co., American Integrity, National States Life, and Central

States Health and Life, declined to provide the information we requested. (We obtained policies and rate information on some of those companies from state insurance departments, but decided not to include these policies in the Ratings, because the data are incomplete.)

We've listed several policies twice, once with their home-care provisions and once without them. We've included two policies sold by MidAmerica Mutual Life, as well as both the old and new policies underwritten by Prudential for the American Association of Retired Persons.

The Ratings show the plans based on the daily benefit amounts and waiting periods that companies said were selected most often by their customers. If a company didn't tell us which of its plans was most popular, we chose one.

Some of the policies are group policies that have the same characteristics as individual policies. Policies sold by AARP are an example.

To rank the policies, we paid special attention to six main features that contribute to a policy's overall quality: nursing-facility coverage, home-care benefits, restrictions, renewability, relationship of benefits to premium and other aspects of pricing, and underwriting (the process of selecting applicants for coverage). We assigned the most points for quality of coverage and absence of restrictions. We also give bonus points to policies with liberal home-care provisions.

We also examined each company's financial stability, as judged by the A.M. Best Co., which rates insurance companies from A+ (superior) to C (fair). If a company's Best's rating is B or poorer (or if the company is not assigned a rating), we've considered it a disadvantage, since a low rating suggests some risk the company may not be around to pay future benefits.

Should you buy?

We don't recommend long-term-care policies for anyone under age 60 unless the policy offers a good way to keep benefits current with inflation in nursing-home costs. For those over age 60, a policy from one of the top-rated companies might be a reasonable choice. People whose income and assets are fairly modest should not buy long-term care policies. They would quickly qualify for Medicaid benefits should they need to stay in a nursing home.

The best policies cover care in all three types of nursing facility and offer generous daily benefits and benefit periods. They also have a good price in relation to those benefits.

Even the best policies had minor deficiencies in their coverage, however. For example, the Great Republic policy has a generous $80 benefit, paid for an unlimited period. But the policy restricts the benefit to a lower amount for the first 50 days of skilled care. It compensates for that restriction somewhat by not requiring a waiting period before paying benefits. And it is the only policy with a built-in inflation adjustment, a highly desirable feature.

The John Hancock policy offers a generous $100 benefit for six years, a period that should cover most nursing home stays, and its coverage has only a few minor limitations. Buying the policy could be a problem, however. The company estimates its rejection rate at 20 to 25 percent. A company spokesperson says that this rejection rate could drop as John Hancock agents acquire more experience selling the policy.

The most popular policies sold by Bankers Life and Casualty and its subsidiaries, Bankers Multiple Line, Certified Life, and Union Bankers, offer coverage for care in all three types of facility, and the policy specifically says Alzheimer's disease is covered. But these policies ranked somewhat below the top companies because of their relatively low daily benefit ($50), which is available for only three years for each nursing home stay.

A high premium doesn't always buy higher-quality benefits. For example, compare the American Progressive Life policy with the Life and Health of America policy, which ranked next to last.

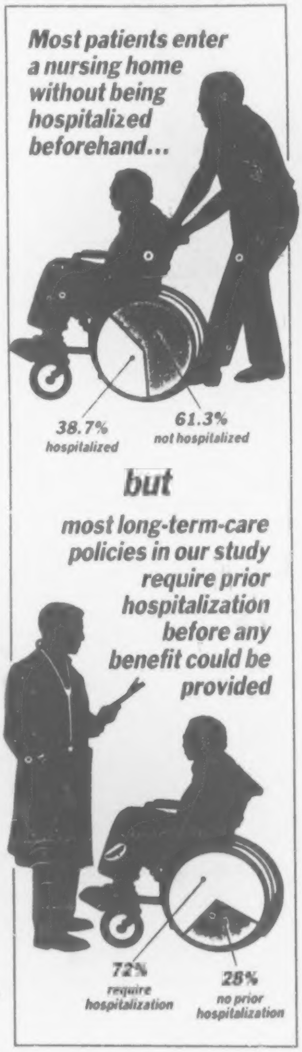
The former provides an $80 daily benefit for a monthly premium of $57.24. The policy offers benefits for three years for one nursing-home stay and five years for all stays. The Life and Health policy offers a skimpy $40 daily benefit (for only two years) yet commands a $100 premium.

Buying a policy through a group doesn't necessarily mean you'll get more for your money. Neither the policy recently sold through the American Association of Retired Persons nor the policy that will replace it this spring ranked highly. They impose a 90-day waiting period before nursing-home benefits begin and pay benefits for only three years. (Visits by home-health-care workers count toward satisfying the 90-day waiting period.) Neither policy, however, requires a stay in a hospital before benefits start.

The old AARP policy has no provision to continue coverage if the group contract is cancelled; the new one does. An AARP spokesperson says that people who have bought the old policy have assurances from AARP that coverage won't end.

Insurance companies have come up with some innovative ideas. For example, Metropolitan's Security Care Agreement for Group Health Cooperative of Puget Sound provides service in accordance with the principles of a health maintenance organization. Patients receive service instead of dollar benefits. Since the benefits offered by this plan will cover 100 percent of the actual cost of nursing-home care, they should hold up well against inflation.

This plan did have its drawbacks. It paid benefits for a relatively short time (4 years), lacked a waiver of premium, and had a high estimated rejection rate (20 to 30 percent).



Must you die poor?

Mary Ann Mattingly, of Indianapolis, looked forward to a comfortable old age when her husband James retired from his job as a security guard at the Eli Lilly Co. The Mattinglys lived reasonably well on the $744 a month he received from his company pension plan and from Social Security. They even managed to dine out on occasion.

But James's health slowly began to deteriorate. He became confused. He could no longer walk. He needed someone to help him eat. In 1979, at the age of 72, he checked into the Eastside Health Care Center, an Indianapolis nursing home. By the time James died in 1986, the Mattingly family, despite a lifetime of work and the security of a pension, had sunk into poverty. It was either that or do without the care James needed in his final years.

James's first year in the nursing home cost $12,000—about $3000 a year more than the family's total annual income. Mary Ann applied for help from Medicaid, the Federal and state program that helps the poor pay their health-care bills. She learned she was too rich for Indiana's Medicaid program. The Mattinglys had accumulated $5000 of Eli Lilly stock, $3000 in a passbook savings account, $2000 in life-insurance cash value, $5000 in a certificate of deposit, and $300 in a Christmas-club savings plan.

The only way Mary Ann could keep James in a nursing home was to become impoverished. Medicaid pays the bills only after the family assets and income run out. That usually doesn't take long. On average, 13 weeks elapse from the time a patient is admitted to a nursing home until the spouse left at home is impoverished. It took Mary Ann Mattingly only nine months to spend on nursing-home care most of what the family had accumulated. When she was poor enough, Medicaid stepped in.

Each state has its own Medicaid rules. Indiana allowed Mary Ann to keep $2250 of her family's assets plus her household furnishings. (If she'd owned a home, she could have kept that, too.) But nursing-home care still took $477 a month of the Mattinglys' $744 monthly income, leaving $238 to cover rent, gasoline and insurance for the car, and food, and $29 for James's incidental expenses.

Once she became poor, Mary Ann, who had never taken a hand-out in her life, qualified for food stamps—as much as $75 worth a month, but more often $30 worth.

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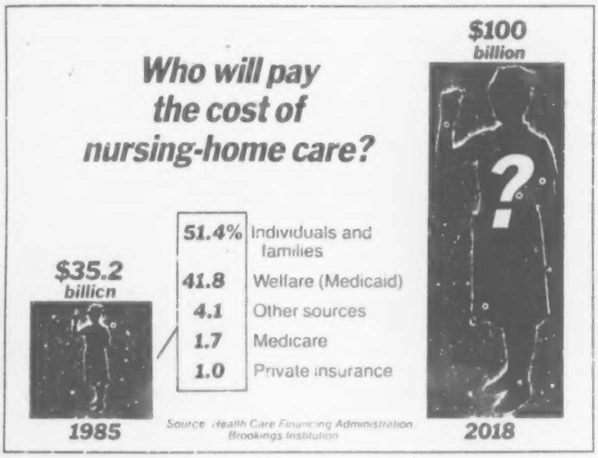

Source: Health Care Financing Administration, Brookings Institution

Special Federal funds to help poor people pay for utilities sometimes paid for her heating bills.

The Medicaid rules did give Mary Ann one way to protect her assets and avoid poverty: divorce. After 32 years of marriage, she wouldn't consider it.

"It was horrible," says Mary Ann. "There's still anger in me. Nobody can understand until they've experienced it. A lot of people today don't know what they have in store." Indeed they may not.

In the year 2030, people over 65 will make up 21 percent of the population, up from 12 percent in 1985. The fastest-growing age group is the "old-old," people 85 and older. Their need for long-term care is greatest.

Nursing-home costs have gone up almost as fast as the age of the population. The average annual cost of a year's stay in a nursing home is now about $22,000, but the cost rises to as much as $45,000 in metropolitan areas such as New York City. Medicaid pays for nearly half of those stays. Federal expenditures for nursing-home care grew tenfold from 1965 to 1980 and will quadruple by 1990.

For years, health economists and social-service planners have seen the shadow of these costs looming. But long-term care for the elderly has only recently won a place on the national agenda—as a seemingly intractable problem for the debt-ridden Federal government, as a giant financial headache for state governments that share the cost of the Medicaid program, as a painful crisis for more and more families, and lately as a marketing opportunity for insurance companies.

What to do?

In 1986, the Secretary of Health and Human Services, Dr. Otis Bowen, issued a report pointing out that Medicare, the health-insurance program for the elderly,

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UPDATE

PAYING FOR A NURSING HOME

Our May 1988 report found many policies for long-term care to be expensive and riddled with loopholes. The picture has improved, but it's still far from perfect.

After a bout with double pneumonia, Anna Indergaard entered a nursing home in Carrington, N.D., expecting that the policy she had bought six months earlier from Acceleration Life would pay the bill. But as soon as she filed for benefits, Acceleration dug into her health history and found that in 1980 she had been hospitalized for a circulatory condition. The company canceled the policy even though the circulatory condition was not the ailment that sent her to a nursing home. Had it known about this disorder, Acceleration said, it would not have issued the policy.

The application had asked Indergaard to list only the health problems she had in the last five years. She didn't mention the circulatory condition since it had occurred seven years earlier. Nevertheless, Acceleration said she had lied on her application.

Only after the North Dakota Insurance Department intervened did Acceleration agree to pay Indergaard's nursing-home bills.

Viola Holland of Watsonville, Calif., paid one annual premium of $1505 for a long-term-care policy sold by Pioneer Life. During the sales presentation, Holland told the agent that she had been hospitalized for valley fever, which might eventually cause kidney failure. Yet the agent marked "no" where the application asked about kidney diseases and disorders.

Sometime after the agent delivered the policy, along with the application she had signed, Holland discovered the misstatement and immediately notified the insurance company. The company told her not to worry; she was covered because she didn't have kidney failure at the time she signed the application.

When her kidneys did fail nine months later, she entered a nursing home. But instead of paying the $80 daily benefit, Pioneer rescinded Holland's policy and later returned her premiums—insisting that Holland had misstated her medical history.

After five months in the nursing home, Holland died. Eventually her family received $9200 from Pioneer Life, but not without the help of the California Department of Insurance and a senior-citizens advocate, who wrote numerous letters on their behalf.

Ella Vallier was 93 when an agent persuaded her to buy a long-term-care policy from Providers Fidelity. During the sales pitch, Vallier's granddaughter told the agent that her grandmother had a heart condition but had refused to be hospitalized for a confirming diagnosis. On the application, the agent wrote "no" where it asked if the applicant had ever refused advice to go to a hospital or nursing home. "Usually with the heart they go just like that," he reassured Vallier's granddaughter.

Nearly a year later, Vallier suffered a stroke, which was unrelated to her heart condition, and was sent to a nursing home in Santa Cruz, Calif. When her family filed for the $60 daily benefit under the policy, the company refused to pay.

The Vallier family was not as lucky as the others. The California Department of Insurance has so far been unable to persuade Providers Fidelity to pay $20,000 in benefits to Vallier's heirs.

An insidious practice

Indergaard, Holland, and Vallier were all victims of "post-claims underwriting"—the practice of checking a policyholder's medical history only after a claim is filed, instead of when an application is taken. If, within two years, a company discovers an undisclosed health condition that would have caused it to reject the application in the first place, it may deny benefits, cancel the policy, or both.

Driven by the need to grab a share of the growing market for long-term-care insurance and pressured by agents unwilling to wait weeks for their commissions while the home office checks an applicant's medical records, some companies determine applicants' eligibility simply by asking them a few questions about their health.

If the answers indicate no serious past diseases or medical conditions, the company usually issues the coverage without checking the accuracy or the completeness of the answers. If the answers do reveal a medical condition, the company may either reject the application or check the applicant's medical history more thoroughly before issuing a policy. Only a few companies, such as AMEX Life Assurance, require an attending physician's statement with every application.

But companies using those lax procedures for determining eligibility can suddenly get tough if a policyholder is admitted to a nursing home during the policy's "contestable period"—two years in most states. During that time, a company can legally rescind a policy and return all premiums if it discovers a policyholder has misrepresented relevant facts on the application and it relied on those facts in issuing coverage.

After the contestability period is up, companies can still deny coverage if they can prove fraudulent statements were made on the application. If the undisclosed condition would have disqualified the applicant, the company may rescind the policy even if the condition is different from the one that ultimately put the policyholder in a nursing home.

Cracking down

"These issues are prevalent throughout the country," says Earl Pomeroy, vice president of the National Association of Insurance Commissioners (NAIC). The NAIC, which writes model laws for all states, is considering a number of options to crack down on underwriting abuse. These would require that:

■ Applicants, rather than insurance agents, fill out the medical questions on the application.

■ A prominent notice go on the application warning prospective policyholders to answer all questions truthfully.

F Insurance companies report all policies they've rescinded, so that state insurance departments could spot abuses and police companies more adequately.

G An attending physician's statement be submitted for all applicants over age 75 or 80.

But we think stronger medicine is needed. The contestable period should be reduced from two years to one year. That would force the companies to evaluate applicants at the outset, before they need nursing-home care—and the money to pay for it.

Trapped by technicalities

Policies for long-term care may hold other traps—language that companies choose to interpret narrowly and limitations that insurers can use to reduce or deny coverage.

Margaret Ballard, age 86, purchased a policy from Equitable Life and Casualty. Last December, after a fall left her unable to walk, she was admitted to the Cascade County Convalescent Nursing Home in Great Falls, Mont. There, she fell again, breaking her arm and injuring her back. After a brief hospital stay, she returned to the nursing home for skilled-nursing care at a cost of $59 a day.

Equitable paid for 10 days of skilled-nursing care, but then it decided that Ballard was no longer eligible for the skilled-care benefit—even though Medicare said she needed skilled care and was reimbursing the nursing home accordingly. Equitable claimed that the policy required Ballard to take physical therapy to qualify, despite the fact that the injury to her arm made such therapy impossible for a time. Without the therapy, Equitable said, she qualified only for custodial care, which helps with such routine activities as eating, bathing, and dressing. It reduced its payment to the $40 custodial benefit the policy allowed.

A fellow patient at the nursing home also had a policy from Equitable, but he didn't collect a dime. Medicaid, which paid his bill, said the man needed intermediate care, which involves daily nursing but not 24-hour attention. But according to Equitable, the man needed only custodial care, and his policy didn't cover that.

"Insurance companies are making their own rules as far as what's covered in skilled care," says Jeff Piper, operations administrator of the nursing home. "Now it doesn't matter whether Medicare or Medicaid says a patient needs skilled care. I'm seeing more and more people turned down because they don't meet the policy's guidelines."

The insurance industry has no standard definitions for "skilled," "intermediate," or "custodial" care. One company's definition of skilled care may differ from another's, and both may differ from Medicare's. If a person's medical condition doesn't fit the policy's definition, he or she may be out of luck.

(Ken Surfass, corporate counsel for Equitable, concedes that there can be arguments over what constitutes skilled care, especially in cases where Medicare doesn't pay.

PROTECTING YOURSELF

RULES TO REMEMBER

It's impossible to know in advance how an insurance company will behave when you need to file a claim on a long-term-care policy. Until more claims have been filed, and until insurance regulators make public the records of companies engaging in post-claims underwriting, you must protect yourself. These steps will help:

1. Answer all questions on the application truthfully and completely. If an agent tells you not to list some health condition, do it anyway. Insist that the application be filled out truthfully—or find another agent.

2. During the free-lock period (the 30 days after the policy is delivered during which you can cancel and get your money back), check the application you signed. The application becomes part of the policy, and the company can later use it to rescind your coverage. Make sure the agent has answered the questions correctly and hasn't changed any of your answers. If you spot any errors, notify the company at once, and try to get the company's response in writing.

3. Beware of agents who insist they can get you coverage in 24 or 48 hours or some similarly short time. That may be a signal the company will wait until you file a claim to determine your fitness for coverage. You may be better off with a company that examines your medical history and requires an attending physician's statement before issuing the policy. A policy from a company that has easy issuing requirements may be of no value later, when the company decides to take a harder look at you.

4. Be wary of a company willing to issue a policy to someone over age 85. A company eager to issue coverage to very old people may have less intention of paying the claims that inevitably will follow. Check with your state insurance department to see if it has information on how the company pays claims, especially those made by the very old.

5. Avoid policies that require you to be hospitalized before a nursing-home stay and those that require a prior level of care before benefits are payable. Even though the model law written by the National Association of Insurance Commissioners prohibits such restrictions, not all states have adopted the model, and there are still policies sold with these limitations. They could cause you or your family a lot of grief later.

6. Carefully read the policy's definitions for levels of care. If the policy says it pays for skilled, intermediate, and custodial care, make sure it pays for them in any type of facility, not just one specializing in skilled-nursing care. If the definitions seem too restrictive, look for another policy. Some policies make no distinction among levels of care. They will pay for any type of care in any licensed facility. It's worth considering these less-restrictive policies to avoid haggling over definitions when the need for care arises.

7. Buy one good policy. If you have a policy and want either higher benefits or less-restrictive coverage, ask your present company about upgrading it. Upgrading from your own company may be cheaper than buying a new policy from a different company and paying the company's expenses, including the agent's commission, all over again. (Some companies offer policyholders a chance to upgrade without rechecking their medical condition. Ask if your company will do this. However, if you have a chronic health condition, you may not be able to switch.)

If your company won't upgrade your policy by, for example, eliminating the requirements for prior hospitalization or prior levels of care, you should shop for a new company. But keep your old policy until you have received the new one.

8. If you own a policy, make sure a friend, family member, or your doctor knows where it is, when the premiums are due, and how to submit claims to the insurance company.

To eliminate such arguments, Equitable's new policies no longer make a distinction between skilled, intermediate, and custodial care. Policies now coming on the market simply say Equitable will pay for any long-term care in a licensed facility.)

Distinctions between levels of nursing-home care may deprive patients of benefits in other ways, too. When Gordon Finke entered a North Dakota nursing home for numerous ailments, Medicare determined he needed skilled-nursing care and paid for 25 days of it. National States Insurance, the company that sold his long-term-care policy, said he needed only custodial care and refused to pay the $60 benefit the policy provided for skilled care. Then it also refused to pay any benefit for custodial care, because the policy said custodial care would be covered only after five days of skilled or intermediate care had been paid for by the policy.

By the year 2000, more than eight million Americans who are 65 and older will need some kind of long-term care. Some 40 percent of all the elderly will spend time in a nursing home before they die.

Some recent improvements

When we reported on long-term-care policies in 1988, this type of coverage was so new that insurance companies knew little about the potential cost of claims. They therefore riddled their policies with restrictive language intended to limit coverage and reduce the amount they would eventually have to pay to policyholders.

We followed up with a new survey this summer to see if insurers were improving the terms in new policies offered consumers. Here are the changes we found in the major restrictions noted in our 1988 report:

Prior hospital stays. Seventy percent of the policies we examined last year paid for a nursing-home stay only when it was preceded by at least three days in a hospital for the same condition that required nursing care. Usually a person had to enter a nursing home within 30 days after leaving the hospital. Other policies required a "prior level" of nursing care before benefits are paid—that is, they would pay for "custodial care" only after a period of "skilled" or "intermediate" care paid for by the policy.

About half of the 24 insurers responding to our 1989 survey said they were phasing out policies requiring prior hospital stays, while others said they had eliminated requirements involving prior levels of care in their new policies. John Hancock, for instance, said it no longer required 14 days of skilled-nursing care before paying custodial benefits.

Insurers are responding not only to public criticism of these limitations but to the model law and regulations drafted by the NAIC. Those outlaw policy restrictions related to prior hospital stays and prior levels of care. Two-thirds of the states have adopted either the model law or the regulations. Insurers selling in states that haven't yet passed the model or that have adopted weaker provisions are free to continue selling the restrictive policies, and a few said they would do so as long as they could.

In states where the restrictive policies remain legal, some companies now offer a choice between policies that require a prior hospital stay and more expensive policies that don't. Our 1988 Ratings showed only one company, MidAmerica Mutual, that offered coverage with and without the prior-hospitalization rule.

Among companies citing a price difference between the two plans, differences vary substantially. At Equitable Life and Casualty, the difference is only 5 percent, but at Continental Casualty, it's 30 percent. One company in our 1989 survey, Federal Home Life, removed the requirement for prior hospital stays but did not increase premiums.

As an alternative to prior hospital stays and prior levels of care, some companies have begun using "activities of daily living" standards to determine if a policyholder needs nursing-home care. These standards measure whether a person can perform such routine tasks as walking, eating, bathing, or dressing. If a policyholder is unable to perform, say, two or three of these activities, the company considers the person eligible for nursing care and pays benefits.

Requirements for prior hospitalization and prior levels of care are overwhelmingly important in determining whether you will actually receive benefits from your policy. The table on the next page points out which companies still sell policies with those restrictions and which ones are designing new policies using the less onerous activities-of-daily-living standards.

Preexisting conditions. Most policies in 1988 required a waiting period before they would cover policyholders for health conditions present at the time the policy was written. Since our earlier survey, some companies have eliminated or shortened these waiting periods. AMEX Life Assurance now has no preexisting-conditions clause in its newest policy, and Colonial Penn has decreased the waiting period on its policies from 12 months to six.

Guaranteed renewability. In 1988, we found that some policies were "conditionally" renewable; that is, companies could refuse to renew a policy as part of a decision to abandon an entire class of policyholders, such as all those living in a particular state. Now many of these companies have made their policies renewable for the policyholder's life. In states that have adopted the NAIC model regulation, individual policies can no longer be canceled just because an insurance company wants to dump a group of policyholders. The model regulation also protects those who have bought long-term-care coverage through groups. If the group policy is canceled, certificate holders can continue their coverage at the same rates, or they can convert to a new policy that is substantially like the old one.

Alzheimer's disease. In our first look at these policies, we found that many were ambiguous about coverage for Alzheimer's and related degenerative and dementing diseases, conditions that often send people to nursing homes. Some companies now report that their policies specifically spell out that those diseases are covered. The NAIC model regulation requires that companies not exclude coverage for policyholders who develop Alzheimer's disease.

Inflation protection. In 1988, few policies had provisions to increase benefits in line with inflation. More companies are now selling riders that give policyholders the option of coverage indexed to inflation. Lack of inflation-protection can be a significant drawback with long-term-care policies, especially if they are purchased by people who are unlikely to use them until 10 or 20 years pass.

Home-care benefits. Most of the companies in our earlier survey offered home-care benefits, which pay for nursing care in a person's home. But they usually required a stay in a hospital or nursing home first. A few companies have eliminated prior hospitalization and prior levels of care; others have lengthened the period of time they will pay for home care.

Nonforfeiture benefits. These benefits, which are required in life-insurance policies, return to policyholders part of what they have paid for the policy if they choose to cancel their coverage or if coverage lapses because they've forgotten to pay the premium. Last year virtually none of the companies in our survey offered nonforfeiture benefits on their long-term-care policies.

Of the companies responding to this year's questionnaire, only four—Bankers Life and Casualty, Metropolitan, Penn Treaty Life, and Travelers—offer some kind of nonforfeiture or return-of-premium benefit. Companies not offering these benefits say they would add to the cost of their policies. AMEX Life Assurance, for example, told us it decided to skip such a benefit in order to keep premiums lower.

Even though the model law and regulations mandate substantial improvements in long-term-care policies, they do nothing to improve the old policies. There are some 800,000 of these older, more restrictive policies still in force. ■

LISTINGS

Long-term-care policies

The table below shows whether the 24 companies responding to this year's questionnaire have changed their policies since our last survey. The two righthand columns show how each company treats two key eligibility requirements for paying benefits: prior hospital stays and "activities of daily living" (ADL) standards. Many policyholders have not received benefits because of requirements for prior hospital stays. The companies are listed alphabetically.

1 Last year's policy. Indicates whether the company is still selling the policy we rated in May 1988.

2 No prior hospitalization. Indicates that the policy we rated last year did not require prior hospital stays.

3 New policy. Indicates whether the company is selling a new policy.

4 Dual option. Indicates whether the company offers a choice of policies, one with and one without requirements for a prior hospital stay.

5 ADLs. Indicates whether the company is planning to use "activities of daily living" (ADL) standards to determine eligibility for benefits, rather than prior hospital stays and prior levels of care. ADLs look at a patient's ability to perform routine daily activities such as eating and bathing.

Company	Last year's policy 1	No prior hospitalization 2	New policy 3	Dual option 4	ADLs 5
Aetna	✓	—	—	✓	[1]
AIG Life	✓ [2]	—	—	✓	✓
AMEX Life Assurance	—	—	✓	—	✓
Bankers Life and Casualty	✓ [2]	—	—	—	—
Blue Cross of Washington & Alaska	[3]	✓	—	—	—
Colonial Penn	—	—	✓	—	✓
Continental Casualty	✓	—	—	✓	—
Equitable Life and Casualty	✓ [2]	—	✓	✓	—
Farwest American	✓	✓	—	✓	—
Federal Home Life	✓ [2]	—	—	—	—
Finger Lakes Long Term Care Insurance Co. (Blue Cross Blue Shield of Rochester)	—	✓	✓	—	[4]
Great Republic	✓	—	✓	—	—
John Hancock	✓ [5]	✓	—	—	✓
Life Insurance Co. of Connecticut	✓ [6]	—	✓	—	—
Metropolitan	—	✓	✓	—	✓
MidAmerica Mutual	✓	[7]	—	✓	—
Mutual Protective	✓	✓	—	—	—
NN Investors	—	—	✓	✓	—
Penn Treaty	✓	—	✓	✓	✓
Prudential/AARP	—	✓	✓	—	—
Reserve Life	✓	—	—	—	—
Travelers	—	✓	✓	—	✓
United General Life	✓	—	—	✓	—
World Life & Health of Pennsylvania	—	—	✓	✓	✓

[1] *Company refused to answer question.*
[2] *Eliminated requirement for prior hospital stay from last year's policy, or made option available as a rider.*
[3] *Discontinued last year's policy and is not selling a new one.*
[4] *Uses assessment tool that evaluates functional, cognitive, and behavioral impairments.*
[5] *Selling only comprehensive version.*
[6] *Sold only in Rhode Island.*
[7] *We evaluated policies with and without prior hospitalization requirement.*

Chairman **Rockefeller**. Thank you very much, Gail. The first question will be from Congressman Gradison.

Representative **Gradison**. Thank you, Mr. Chairman. This excellent presentation by this particular panel brings into focus the question of the extent to which the private sector can play a role. I have always figured in the end that we would end up with some kind of a partnership, therefore, the question of how large a role can be played by the private sector becomes a very important issue.

The only systematic review that I have seen of that subject, and there may be other reviews that I haven't seen, was the Brookings Report which attempted to project the extent to which the private market would be able to meet this long-term care need.

Let me hasten to say it was clear that it wouldn't meet the whole need but it would meet a part of the need. The question is how large a part? There is a lively debate taking place in academic circles about the Brookings projections and the assumptions upon which they were based.

This is background for a question which, as far as I'm concerned, if you aren't able to answer now and you want to submit something for the record, that would be fine. What I'm looking for is the input of each of you with regard to what you believe—what part of the problem could be met by the private sector in 20 or 30 years in the future, and why you think it. What assumptions do you make in reaching your conclusion?

Mr. **Schweiker**. Well, I'll start, Mr. Chairman, if that's all right. I believe a strong part of the market could be met by the private sector, but I do want to start off by saying that we need a public-private partnership. No one can solve all the problems, so we start on that basis. It somewhat blows my mind that we have $4.5 trillion of face value life insurance sitting out there that people can tap and will tap.

Here we have a survey that says 60 percent of the people would probably have included a long-term care rider in their life insurance policy if they had been given the opportunity. So, the key issue with Brookings is, if you give that kind of tax consideration to long-term care insurance that you do for health insurance, will people's behavior change. In response to the question about the high income people, which I strongly take issue with, I'm talking 103 million people that have these policies.

There are not 103 million high income people out there. This would solve a significant chunk of the problem. We do need the public sector market. We do need that as a partnership. We close our eyes to a tremendous solution if we ignore or do not encourage the private sector market.

Dr. **Schramm**. I'll take a go at it as follows. Dick says we have 103 million people with life insurance contracts. We have 180 million people who are covered either by commercial health insurance or Blue Cross plans. So, there is ample evidence that at least on two frontiers, income protection and health protection, there is a vigorous private market.

When it comes to long-term care, it is hard to forecast, but I think there is some data that suggests that the number of people potentially covered is a lot larger than the Brookings estimate which has already aged probably 18 months when the phenomenon may only be about 48 months old in terms of a developing private market.

That is, we have at this moment a lot of experiments going on with life insurance vehicles that Dick has testified to. We have the invention out of whole cloth of all kinds of new specific long-term care insurance vehicles and the experimentation is phenomenal. We have programs that are offered by companies that are modeled on disability insurance that don't relate at all to where the care will be given, but rather to activities of daily living, such that payment obligations spring when someone may, in fact, be deficient in terms of the activities of daily life.

Long-term care policies may also be triggered by much more traditional routes of a physician saying it's time for you to move to a nursing home for a month or so. As to the specifics of how large this potential market would be, we do know that Brandeis University has estimated, subsequent to the Brookings estimates, that the potential market might be 45 percent of the elderly population.

I think at this point it would be hard to estimate, but I should think it would be certainly in that neighborhood and potentially higher. It is very significant in making those estimates that the largest single takeup of the long-term care product is in the employer-sponsored market where the average enrollment age is about 42 years, which suggests that there is an increasing consciousness among younger workers that if they begin to pay and, assume the responsibility early in life, many people can be covered.

There are also estimates being developed at Boston University and I should think—my own hunch is that at some point the private market might reach well up into the 60- or 70-percent range.

Ms. **SHEARER**. I have a somewhat less optimistic view, and I would like to just comment briefly on the Brookings study. There are assumptions about how many people would buy private long-term care insurance are quite optimistic, in our view, and in one of their estimates, they judged that 25 percent of people could be covered by private long-term care in the year 2018.

The interesting thing about that number is that the related decrease in Medicaid—the decrease in people whose nursing home care would be covered by Medicaid is only between 2 and 3 percent, and that highlights how this type of insurance is geared to people who would not qualify for Medicaid quickly.

Turning again to your question about what the role of the private market should be, Consumers Union's first choice is to have a largely Government program. If it were the judgment of this Commission that there should be a large role for the private market, one way to do it on a low budget option would be for the Government, the Congress to design an optimal long-term care policy, possibly two or three different levels of coverage and have the private market bid, through competitive bidding, for the right to market that.

By doing it this way, you could draw on the best of the private sector instead of what we have today which is a great variety in quality of policies. I would also just turn to the experience with the Medigap market which has not been very positive after over 20 years—there are still terrible abuses and we're concerned that the long-term care market will follow in the Medigap market footsteps.

Representative **Gradison**. Thank you all, and thank you, Mr. Chairman.

Chairman **Rockefeller**. Thank you. Dr. Davis?

Commissioner **Davis**. I'd like to ask Mr. Schramm—in his recommendation that we continue Government support of long-term care data collection and research, how good is our data now and how much research is going on? How well is Government supporting it now?

Dr. **Schramm**. Well, I think——

Commissioner **Davis**. Do we really have adequate data on long-term care figures? Is there significant research going on?

Dr. **Schramm**. Dr. Davis, I'm really not the expert on that. It seems to me that from the insurance prospective, we are somewhat crippled in our ability to make underwriting estimates, actuarial estimates, and so forth, largely by the absence of good demographic data and data related to what the needs of elderly people are in a scientific way. I think a lot of information is being developed.

There are centers for gerontology at a number of universities that are flourishing. Our basic entreaty this morning is that more of this needs to be done from the public perspective in encouraging this type of basic research.

Commissioner **Davis**. So, you're probably recommending not only continuation but expansion of governmental support for both data collection and research in the field?

Dr. **Schramm**. Yes, Dr. Davis.

Commissioner **Davis**. Thank you.

Commissioner **Balog**. My question has to do with the use of cash values and policies to buy long-term care without incurring a tax liability. How many people would be able to buy these policies? Take a 65-year-old person with whatever your typical policy cash value would be for that person. How much long-term care insurance could he buy? How many years before he would exhaust the cash value of the policy?

In other words, is that a major solution for a large number of people.

Mr. **Schweiker**. Well, I'll take a stab at it and maybe Carl would too. The fact that we have already put all this money out there, it's not like you have to start from scratch and say, have a 65-year-old build up a pool that he can draw on. When a 65-year-old has a pool and a reservoir, and right now the average policy being sold today is in terms of $50,000 policy—even the ones that are already out there—they can use that almost instantly to start. It all depends on the size of the policy and the kind of benefits they want.

The typical policy pays about 2 percent of the face value per month. That just happens to be the first prototype. There is no reason why you couldn't increase that to 4 percent a month to meet the needs. The other real big advantage, if I were sitting on that side of the aisle as I used to do, that just screams for some attention, is that this doesn't cost the Government literally 1 red cent to unleash $4.5 trillion of potential assets.

All of this presently is not taxed as death benefits. So here you're just being asked the public policy question if we unleash $4.5 trillion of assets for a good social use a little earlier than it would otherwise have been at virtually no cost to the Government—so, to answer your question a little more specifically, it is difficult to get all the figures we need, but even if the figures are off by a quarter of what we're talking about, you're still putting $1 trillion more of assets on the line to solve the problem in the private sector.

So, you can err an awful lot with $4.5 trillion in terms of your estimates. Our survey shows 60 percent. Carl I think mentioned something around 40 or 50 percent. There is quite a bit of opportunity out there for a 65-year-old that has kept his insurance policy.

Chairman ROCKEFELLER. Let me follow up, Dick, with you a little bit. Obviously, we've got to get something done in long-term care. It seems to me, from your testimony, that you support the system which is very similar to what we've got now, which offers tax incentives and encourages employers and individuals to buy private health insurance.

Many individuals find private long-term care insurance unaffordable and most private insurance policies offer insufficient benefits. In addition administrative costs account for up to 40 percent of the premium, in some cases.

You are suggesting essentially, it seems to me, the same thing for the future, except that you're saying that if people who were 35 years old and 40 years old would start buying long-term care insurance that would make it more affordable Of course, most people don't do that and the Government can't require people to purchase private long-term care insurance. When you're 40 or 35, you think you're going to live to be 200 years old.

So, what are you suggesting that is new?

Mr. SCHWEIKER. What we're suggesting, I think you misunderstood my $4.5 trillion. There are 100 million people out there that have guarantees of $4.5 trillion if they die. What is brand new and what would unleash the genie out of the bottle in the private sector is to give the companies and the policyholders the right to put a rider on those existing policies, right now, so that they could advance the death payment to take care of long-term care.

There is $4.5—we're opening the door on $4.5 trillion that is out there now. That's why this proposal that we have made changes the ball game dramatically overnight by doing two or three things. One is what I just said—unleashing $4.5 trillion already saved, already there, waiting to be put to maybe another good social use.

The second is the group insurance. We worked with IRS and Treasury for 1 year to get a ruling that allows us not to pay tax on the revenues we set up when we sell long-term care group insurance. We've gotten that. We still need more help. We need to clarify what the impact to the individual is so that he isn't taxed when he receives the benefit and when the employer offers it. We need more help. That's a big change.

Chairman ROCKEFELLER. Gail, how would you respond to that?

Ms. SHEARER. Well, I'd like to comment first on one point that Mr. Schweiker made about this not costing the Federal Government 1 cent. Whenever you give a tax credit or a tax preference, of course that costs the Government money. I'm real concerned that nobody get the impression that this is without cost.

Chairman ROCKEFELLER. Do you disagree with that Dick?

Mr. **Schweiker**. No, she's not listening. She's not listening to what I'm saying. There is $4.5 trillion now that already has no tax liability when it is paid as a death benefit. You're simply saying instead of using it at death, use it for long-term care help prior to death. It's not going to be taxable now, so there is no charge to the Government. I can't make that point too clear.

Ms. **Shearer**. Well, that must have been from another part of his testimony. I do think I heard some talk about suggestions, recommendations for tax preferences and tax credits and, of course, whenever you do that you're taking money from all income levels through the tax system and you're basically benefiting relatively higher and middle income people. We do think—another point about the group long-term care insurance market—it has the potential of decreasing the administrative costs, which is wonderful.

One of our biggest concerns, I think, is that we hope we don't have to wait 30 or 40 years for a system that is going to improve the long-term care problem. An employment-based system is going to take some time to have an effect.

Also, spouses and parents are subject to underwriting in group plans, therefore, group systems have the problem of not being accessible to people with existing health risks.

Chairman **Rockefeller**. Dick, do you want to respond to that, or Carl?

Mr. **Schweiker**. I just want to repeat one more time—you can get 100 million people to do it instantly. You don't have to wait 30 years, or 40 years——

Chairman **Rockefeller**. How do you do that?

Mr. **Schweiker**. You simply change the tax law to treat it basically as a health insurance policy so that they can use their life insurance values for long-term care insurance.

Chairman **Rockefeller**. And then, Gail, what do you say to that?

Ms. **Shearer**. It sounds to me like that takes tax revenues through the back door.

Commissioner **Balog**. Wait a minute. Let me see if I understand this, both of you. If the person dies and the life insurance policy has a $50,000 death benefit, the death benefit then goes to his or her estate, correct?

Mr. **Schweiker**. Right, unless paid to a named beneficiary.

Commissioner **Balog**. And there are some——

Mr. **Schweiker**. At no tax.

Commissioner **Balog** [continuing]. Some estate tax, perhaps.

Mr. **Schweiker**. But as income tax on life insurance.

Commissioner **Balog**. So there's no tax there. So this is an opportunity to, if you will, capture savings or redeploy savings for the generation that saved it for their long-term care instead of shifting those savings to the next generation.

Mr. **Schweiker**. That's exactly right.

Commissioner **Balog**. Is that clear to everybody—maybe this is not right. That's what I heard. There is no tax on that revenue——

Ms. **Shearer**. I don't understand why we need a change in policy then. It seems to me that if the Government did nothing, then certain tax revenues would accrue to the Federal Government. It seems that the change that is being requested, it sounds to me like it's going to cost the Federal Government——

Commissioner **Balog**. Isn't this the same as having $50,000 in the savings bank and you devote it to long-term care instead of to whatever else you're going to do with the $50,000? These are savings, aren't they? There is no tax——

Mr. **Schweiker**. She's not familiar with the Tax Code that treats life insurance death benefits in this way. It treats life insurance policies so that the $50,000 death benefit is not taxable. We're saying take the money that is not taxable as a life insurance death benefit and use it and make it not taxable for long-term care benefits. That doesn't cost the Government 1 red cent. It is utilizing $4.5 trillion of money out there for another social purpose that we happen to think whose time has come.

Commissioner **Balog**. Now, I know you talk about $4.5 trillion—I'm afraid I missed some of the scope of what this change could mean in terms of numbers of people that would be covered. What proportion—you might have said it, and I know you keep referring to 60 percent and 40 percent. What percentage of the long-term care universe would be helped by this process?

Mr. **Schweiker**. Well, there's 100 million policyholders that would have that opportunity if the Tax Code was changed. Basically, our survey showed that without any education, promotion, or advertising, without any competition from all companies who have products out there, it showed that 60 percent most likely would utilize that in some way.

There is—here is the other point I want to make. There is a new $1 trillion of life insurance policies being written every year. So, if you—forget the retroactivity part of what the people who are sitting on $4.5 trillion of values now, but every year we're writing new life insurance policies for about $1 trillion.

If you make this change, you're going to make people eligible every year to the tune of millions of people. It's just the potential that one has got to be deaf, blind, and dumb not to understand if we can't get that point through about the social opportunity for public policy at no cost.

Commissioner **Balog**. May I suggest that one thing you could do to help this poor soul is to translate this into people and numbers of people better than you've done in your paper.

Mr. **Schweiker**. Well, all I can say is there are 100 million people out there and 60 percent——

Commissioner **Balog**. One missing point. How long would this cash accrued value fund the long-term care benefit? I don't want to fund it from 65 to 71.5 and then, well, that's all gone, now what happens. That's what I'm getting at.

Mr. **Schweiker**. We could give you some estimates on that. I think I can give you some rough figures to say it would be something in the neighborhood of at least 6 months to 2 years which is where a lot of the things run in terms of the average value. It could pay—if you wanted to convert all of your life insurance, you could get a big chunk of your long-term care. If you didn't want to convert all of that, then you could fund a portion of it. It would be up to each individual policyholder to decide whether they want that protection and how long they wanted it.

Chairman **Rockefeller**. We're going to move ahead. I will have a fairly large number of written questions to submit to all three of you. I thank you for coming and spending your time with us.

Our next panel, and our last panel has to do with State programs. Mildred Shapiro, who is the associate commissioner for Medicaid from the State of New York, Department of Social Services; and Diane Justice, who is deputy director of the National Association of State Units on Aging.

We welcome you both. Whoever wants to go first?

STATEMENT OF MILDRED B. SHAPIRO, ASSOCIATE COMMISSIONER FOR MEDICAID, NEW YORK STATE DEPARTMENT OF SOCIAL SERVICES

Ms. **Shapiro**. I have to say, Senator, it feels very comfortable addressing you after having served Nelson Rockefeller for many years when he was Governor of New York.

I am Mildred B. Shapiro, associate commissioner of medical assistance in the New York State Department of Social Services. I appreciate the opportunity to testify before you on alternative financing mechanisms to the present long-term care system.

Rather than bore you with the demographic data and statistics on the shift from acute to chronic and disabling illnesses which you have probably heard all morning, I would like to outline briefly the irrationality of the current financing system and the innovative demonstration which we are contemplating in New York and several other States.

Most elderly Americans who are faced with the rising cost of nursing home care or prolonged home care have one of two alternatives. One, they can spend down almost all of their assets to meet long-term care costs and then rely on Medicaid when they reach the impoverishment level, or two, they can transfer their assets at least 2½ years in advance. Then, they will expect Medicaid to assume the costs when long-term care is needed.

In both cases, Medicaid subsidizes the middle class, but only after impoverishment is faced in the former and loss of financial control in the latter. There has to be a better way. New York State is proposing that the public sector, Medicaid, forge a partnership with the private sector for that broad middle class of mid-to-older age persons who can and should plan for their long-term care needs.

New York is one of eight States which has received planning grants from the Robert Wood Johnson Foundation to develop such demonstrations. As New York completes the planning stage, it is now proposing a demonstration made possible in part by State legislation which received unanimous support in both houses and the signature of Governor Cuomo.

New York has in place the infrastructure to provide a broad range of home and community-based services and nursing homes as well. The price tag has been high. Approximately 75 percent of all publicly funded home care in the country is delivered in New York; 83 percent of all nursing home days of care in New York is funded by Medicaid.

This year the State Medicaid Program in New York alone will spend about $4.2 billion on long-term care for the frail elderly alone. Instead of this heavy reliance on a program requiring a means-test, there should be in place, for those who are financially able to purchase, some minimum duration of long-term care insurance. Such insurance, when used and exhausted, would have the backup of the State Medicaid Program.

Insurance policies participating with the State would have to meet minimum standards established by the State insurance agency. Those junk policies would not be tolerated, like the Art Linkletter variety. Long-term care costs are too expensive to be financed solely out of pocket, solely through private insurance, or solely with public costs.

All of these revenue streams need to be pooled to make coverage affordable. While a social insurance model has the advantage of avoiding gaps in coverage and creating a larger risk pool, the time is not now propitious. The Halls of Congress still reverberate from the fallout over the Medicare Catastrophic Coverage Act.

And the Federal deficit still looms large. Until national consensus is reached, New York believes we must move ahead with a public-private partnership. We have much to learn in the interim, such as defining minimum benefit packages, developing assessment instruments or measures, and defining the insured event.

That point in frailty which triggers eligibility for benefits is much more complex than recognizing that a fire, a flood, or a death has occurred. Finally, inflation protection needs to be studied so that policies can remain affordable when benefits are indexed with inflation.

In summary, we believe a partnership for long-term care insurance offers the public a quality insurance product, protection from impoverishment, control of assets, delay or avoidance of Medicaid expenditures, and a testing ground for future financing and operations.

We urge that consideration be given by this Commission to the support of such a project. I'd be happy to answer any questions afterward.

[The prepared statement of Ms. Shapiro follows:]

Testimony of

Mildred B. Shapiro

Associate Commissioner
New York State Department of Social Services
Division of Medical Assistance

before

The Pepper Commission
United States Bipartisan Commission on
Comprehensive Health Care

Washington, D.C. October 5, 1989

I am Mildred B. Shapiro, Associate Commissioner of Medical Assistance in the New York State Department of Social Services. I appreciate the opportunity to testify before you on alternative financing mechanisms to the present long term care system.

Rather than bore you with a litany of demographic data, and statistics on the shift from acute to chronic and disabling illness which you have probably heard all morning, I would like to outline briefly the irrationality of the current financing system and the innovative demonstration which we are contemplating in New York and several other states.

Most elderly Americans who are faced with the rising costs of nursing home care or prolonged home care have one of two alternatives: 1) they can spend down almost all of their assets to meet long term care costs and then rely on Medicaid when they reach the impoverishment level; or 2) they can transfer their assets at least 2 1/2 years in advance, and expect Medicaid to assume the costs when long term care is needed. In both cases, Medicaid subsidizes the middle class, but only after impoverishment is faced in the former, and loss of financial control in the latter. There has to be a better way.

New York State is proposing that the public sector (or Medicaid) forge a partnership with the private sector for that broad middle class of mid-to-older-age persons who can and should plan for their long term care needs. New York is one of 8 states which has received planning grants from the Robert Wood Johnson Foundation to develop such demonstrations. As New York completes the planning stage, it is now proposing a demonstration made possible in part by State legislation which received unanimous support in both houses and the signature of Governor Cuomo.

New York has in place the infrastructure to provide a broad range of home and community-based services and nursing homes. And the price tag has been high! Approximately 75 percent of all publicly funded home care in the country is delivered in New York; and 83 percent of all nursing home days of care in New York is funded by Medicaid. This year the State Medicaid Program will spend about $4.2 billion on long term care for the frail elderly alone (excluding the mentally disabled).

Instead of this heavy reliance on a program requiring a means test, incentives should be in place for those who are financially able to purchase some minimum duration of long term care insurance. Such insurance, when used and exhausted, would have the back-up of the State Medicaid program. Insurance policies participating with the State would have to meet minimum standards established by the State Insurance Agency. Thus, junk policies would not be tolerated. Long term care costs are too expensive to be financed solely out-of-pocket, solely through private insurance, or solely with public costs. All of these revenue streams need to be pooled to make coverage affordable.

While a social insurance model has the advantages of avoiding gaps in coverage and creating a larger risk pool, the time is not now propitious. The Halls of Congress still reverberate from the fallout over the Medicare Catastrophic Coverage Act. And the Federal deficit still looms large. Until national consensus is reached, New York believes we must move ahead with a public-private partnership. We have much to learn in the interim such as defining minimum benefit packages, developing assessment instruments or measures, and defining the insured event. That point in frailty which triggers eligibility for benefits is much more complex than recognizing that a fire, a flood or a death has occurred. And finally, inflation protection needs to be studied so that policies can remain affordable when benefits are indexed.

In summary, we believe a partnership for long term care insurance offers the public a quality insurance product, protection from impoverishment, control of assets, delay or avoidance of Medicaid expenditures, and a testing ground for future financing and operations. We urge that consideration be given by this Commission to the support of such a project.

NEW YORK STATE MODEL SUMMARY

I. STATE SUPPORT

- New York State will reinsure individuals for all long-term care (LTC) services approved and rendered after the exhaustion of benefits received under a privately purchased insurance policy meeting standards mandated by the NYS Superintendent of Insurance.

- There will be no State subsidy of premiums for purchase of private insurance. Purchase will be open to all ages, but for demonstration will focus on 60-80 year olds.

II. POLICY REQUIREMENTS

- **Services:**

  Institutional Long-Term Care (ILTC): Three years in a residential health care facility qualified as a provider in the Medicare program pursuant to Title XVIII of the Social Security Act.

Home and Community Based Services (HCBS): Nursing, personal, and respite care services provided by a home care services agency, long term home health care services agency, certified home health care agency or long term home health care program, as defined in thirty-six hundred two of the public health law, or a personal care provider licensed or regulated by any other state or local agency. Qualification for reinsurance through use of HCBS will require usage and, therefore, coverage of such services for periods longer than three years. (See Narrative.)

. **Payment:**

Institutional Long-Term Care: Per diem rates should represent a significant portion of patient liability. Minimums will be established average Medicaid rates. Inflation protection will be required. Insurer benefits may be either service or indemnity.

Home and Community Based Services: Carrier payment per day of home and community care will be based on a fixed percentage of the institutional LTC rate being paid when home care services are utilized. (See Narrative.)

. **Other:**

- Policies must be guaranteed renewable.

- Eligibility for payment of benefits shall be premised on receipt of covered services.

- Case managers shall be used to assess eligibility for receipt of benefits and to assist clients in service planning.

- Insurable event criteria will be approximately equivalent among insurers and consistent with New York State definitions.

- Assessment criteria and instruments shall be comparable among insurers and the State.

- Minimum loss ratios will be established by the Superintendent of Insurance for this demonstration; pooling of loss ratios across product lines will not be permitted.

- Insurers will maintain separate premium and loss data for long-term care insurance policies under this demonstration.

III. ADMINISTRATION

- There will be a coordination of data collection between private and public insurers so that information on reinsurance eligibles will be known and tracked.

- There will be two marketing campaigns. The State will market the demonstration program and will devise an identifying logo to be used on qualifying insurance products. Individual carrier products may be marketed by the insurers using the logo. Because the State logo will be a common identifier for all participating carriers, carriers will be asked to contribute to the demonstration marketing and education effort.

IV. MEDICAID COVERAGE

- Persons exhausting their benefits under an approved private insurance policy will become eligible for all long-term care services provided through the New York State Medicaid program for as long as their need for such services continues.

- Those eligible for reinsurance under the Medicaid program will not be obligated to account for any assets that they might have at that time.

- The State retains the right to place asset limitations on those who would be eligible for participation in the demonstration program. (See Narrative)

- Usual income considerations and treatment under the Medicaid program will not apply to persons becoming eligible for Medicaid through reinsurance. The State will, however, require co-payment toward the cost of care received.

Chairman **Rockefeller**. Thank you very, very much. I appreciate what you said about my uncle. He was a good Governor.

Ms. **Shapiro**. He certainly was.

Chairman **Rockefeller**. Diane, we'd be delighted to hear from you.

STATEMENT OF DIANE JUSTICE, DEPUTY DIRECTOR, NATIONAL ASSOCIATION OF STATE UNITS ON AGING

Ms. **Justice**. Mr. Chairman, I am Diane Justice, deputy director of the National Association of State Units on Aging. My comments will focus on the experiences of a growing number of States in creating community systems of care and lessons drawn from these efforts that can be applied to Federal long-term care policy.

Of greatest relevance is the experience of States in establishing a structure through which community services can be effectively delivered and managed. Some of these community long-term care systems are financed by Medicaid. However, the limitations of Medicaid restricts its usefulness in building comprehensive systems of care.

States are increasingly using their own general revenues to create more flexible service options and to reach persons who cannot be served by existing programs. Therefore, States are committing funds either as Medicaid match or for programs using State funds only.

Governors and legislators are as concerned as are Members of Congress about potential costs of community care. They have, therefore, demanded that their State programs be structured to contain costs while providing sufficient support to individuals most in need. Several management strategies are commonly used.

First, States target services to low and moderate income persons who have significant impairments. Tough choices are made in defining eligibility criteria, with full recognition that many older people who need community supports will not be able to receive publicly funded services.

Functional eligibility considers a person's need for assistance with activities of daily living. As program resources expand, this criteria can include a less-impaired population. However, with growing numbers needing long-term care, and modestly growing State program budgets, functional criteria will remain tightly constrained.

Similar dilemmas are present in setting income eligibility. For Medicaid community services, income eligibility is that used for the entire State Medicaid Program. Increasing that criteria for persons of all ages is an expensive proposition, one that few States can afford in the face of other demands on State budgets.

By using State general revenues to support programs, States can serve a broader population but sacrifice the Federal contribution to service costs.

A second strategy used to control cost is the designation of case management agencies to serve as State government's local administrative agents. Case managers develop care plans that authorize the amount and type of services provided to an eligible individual.

In many State systems, it is only through the authorization of a case manager that an individual can receive services.

In assigning service authorization responsibility, States usually prohibit case management agencies from providing services for two reasons. First, States want recipients to get objective advice on service options and avoid suggestions of providers that what we have is what you need.

Second, separating authorization from service provision eliminates a conflict of interest in authorizing more services simply to enhance the financial status of agencies.

The third management strategy used by States is to limit the total cost of care that can be provided to individuals on a monthly basis. Within this constraint, considerable latitude is given to case managers in determining the type and amount of services needed by a recipient. Nonmedical support such as personal care, homemaker, and chore services form the core of State long-term care programs.

While nursing care may be included in some community care programs, the services needed most often respond to limitations in conducting activities of daily living instead of medical conditions.

In summary, States have demonstrated that community care systems can be structured to contain overall costs while providing flexible service packages These efforts have resulted in improved service options, but only for a small portion of the persons requiring care. Current financing of long-term care is not adequate to meet current needs, much less future growth in the long-term care population.

The National Association of State Units on Aging has developed a proposal for Federal long-term care reform. The program structure proposed is similar to successful systems currently operating in a number of States. We believe that an adequate amount of Federal financing will stimulate the development and expansion of such systems, will preserve a role for private supplemental insurance, and will help create a balance in the choices available to persons needing long-term care.

[The prepared statement of Ms. Justice follows:]

NATIONAL
ASSOCIATION
OF STATE UNITS
ON AGING

NASUA

2033 K Street, NW
Suite 304
Washington, DC 20006
(202) 785-0707

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Virginia

DANIEL A. QUIRK, Ph.D.
Executive Director

Statement of

Diane Justice

Deputy Director

National Association of State Units on Aging

Presented to the

United States Bipartisan Commission on
Comprehensive Health Care

October 5, 1989

Mr. Chairman and distinguished members of the Bipartisan Commission on Comprehensive Health Care, I am Diane Justice, Deputy Director of the National Association of State Units on Aging. The membership of the Association is comprised of the 57 states and territorial governmental offices charged with advancing the social and economic agendas of older people in their respective states.

My comments today will focus on the experiences of a growing number of states in creating community based systems of care and the lessons drawn from these efforts that can be applied to the development of federal long term care policy. Of greatest relevance is the experience of states in establishing a state and local infrastructure through which community based services can be effectively delivered and managed.

Since the inception of the Medicaid program states have been responsible for developing detailed policies governing the provision of long term care services provided in nursing homes. During the past decade a significant number of states have also developed systems of community based long term care services. In part these systems have been financed by the Medicaid program, either through the state plan or as part of the home and community based services waiver authority enacted by Congress in 1981. However, states have found that the limitations inherent in these funding sources restrict their usefulness in building comprehensive systems of care. Therefore states are increasingly using their own general revenues to create more flexible service options and to reach elderly individuals who cannot be served by existing federal programs. Regardless of the financing mechanisms used, states are committing their own resources either to match Medicaid program expenditures or to finance programs exclusively with state funds.

Governors and State Legislators are as concerned as are Members of Congress about the potential costs of community care programs. They have therefore demanded that their state programs be structured in a way that contain costs while still providing sufficient support to individuals most in need of long term care. Several management strategies are commonly used in well developed state community care programs.

First, states have targeted services to low and moderate income persons who have significant functional impairments. Due to the limited availability of resources, tough choices must be made in choosing the populations that meet both functional and financial eligibility criteria. These decisions are made with the full recognition that many older people who need community supports will not be able to receive publicly funded services.

Functional eligibility, as measured by state developed uniform assessment tools, considers an individual's need for assistance in carrying out activities of daily living. Usually these assessments are performed either by social workers or nurses who are trained to identify those instances when consultation with another discipline is needed. As program resources expand, functional eligibility criteria can be drawn to include a broader population group; however, with a rapidly growing population in need of long term care services and modestly growing state program budgets, functional eligibility criteria will most likely remain tightly constrained.

Similar dilemmas are present in setting financial eligibility criteria. Available options are determined by both the amount of total program funds and by the particular funding sources used such as state general revenues and Medicaid. For Medicaid community care services financed under the state plan, income eligibility is a function of the criteria used for the entire state Medicaid program. Increasing that criteria for persons of all ages is an expensive proposition, one that few states can afford in the face of other demands on state budgets. Under Home and Community Based Services Waiver Programs, however, states have some flexibility to set higher income standards.

By using state general revenues to support programs, states can serve a broader population group but sacrifice a federal contribution to service costs. Information collected through a telephone survey conducted by the National Association of State Units on Aging in 1987 indicates that most states have adopted cost sharing requirements for receipt of state funded community care services, with the cost sharing amount varying based upon individual income. State considerations in establishing income eligibility criteria are similar to those relating to functional criteria. If the population in need of care grows without a proportional increase in program resources, income criteria could become more restrictive.

A second major strategy used to control program costs is the designation of a case management agency in each geographic area of the state to serve as state government's local administrative agent. These agencies perform two important functions. For older people they serve as a visible entry point into the community care system and provide assistance in identifying and arranging for the provision of needed services. For states case management agencies are the point of local program accountability for translating state policies into service provision.

In particular, case management agencies are often charged with the responsibility of developing care plans that authorize the amount and type of services that will be provided to an eligible individual based upon the results of the functional assessment. In many state community care systems it is only through the authorization of a care manager that an individual gains access to specific program services.

In assigning service authorization responsibilities to case management agencies, states usually prohibit these entities from directly providing program services for two reasons. First, states want program recipients to get objective advice or service options tailored to their own unique needs, thereby avoiding potential suggestions of provider agencies that "what you need is what we've got." Second, separating service authorization from service provision eliminates a conflict of interest in authorizing more services than may be necessary simply to enhance the financial status of provider agencies.

The third management strategy undertaken by states is to place a limit on the total cost of care that can be provided to individuals on a monthly or annual basis. In some states this ceiling is applied to each care plan; in other states care management agencies must keep the average cost of care plans within the state established ceiling. Usually this ceiling is tied to the cost of nursing home care.

Within these contraints, considerable latitude is given to case management agencies in determining the type and amount of services needed by a program recipient. This flexibility is designed to encourage creative responses to individual needs rather than fitting the needs of older people into rigid service categories. A major shortcoming of the Medicare program and of the services available under the Medicaid state plan is the lack of flexibility in the types of home care services that can be provided; available services, therefore, correspond to federal rules rather than to the unique needs of individuals.

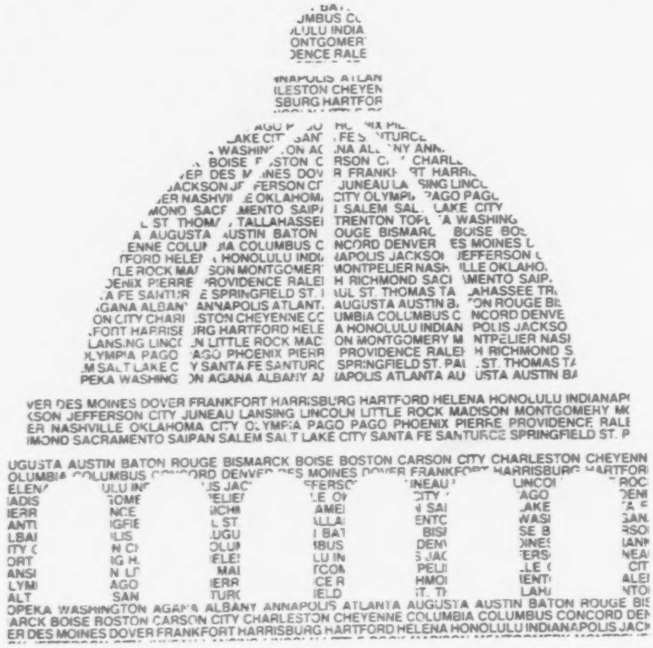
Non-medical supportive services such as personal care, homemaker and chore services form the core of state long term care programs. While some skilled home nursing care may be included in individual care plans, community long term care services most needed by older people are in response to limitations in conducting activities of daily living as opposed to specific medical conditions.

In summary, states have demonstrated that community care systems can be structured to contain overall program costs while providing flexible service packages responsive to individual needs. These efforts have resulted in a vastly improved array of service options and a judicious management of resources, but only for a small portion of the population requiring care. Current structuring and financing of long term care is not adequate to meet the current need, much less the future growth in the long term care population.

Consistent with this perspective, the National Association of State Units on Aging has developed a proposal for federal long term care reform that grows out of state experiences in developing and managing community care programs. We suggest that in order to achieve equitable treatment of individuals across all states, a federally-financed, state-administered, locally-managed, individual oriented system is needed. Within broad federal parameters, significant discretion should be provided to states, enabling them to capitalize on the long term care systems development work already in place and to reflect differences across the country in patterns of human services delivery.

To provide a more balanced approach to the allocation of public long term care resources between institutional and home care services, we suggest that the first federal dollar of coverage support the expansion of home and community based systems of care. Since public financing will not be adequate to completely pay for all program costs, we envision that similar to the role played by Medigap policies, private insurance can provide supplemental coverage for co-payments and for extended nursing home care beyond the publicly financed coverage.

The program structure proposed is similar to successful systems currently operating in a number of states. We believe that an adequate amount of federal financing will stimulate the development and expansion of such systems, will preserve a role for private supplemental insurance and will help to create a balance in the choices available to older persons in need of long term care assistance.



Federal Long Term Care Reform: A Proposal by the National Association of State Units on Aging

NATIONAL
ASSOCIATION
OF STATE UNITS
ON AGING

NASUA

2033 K Street, NW
Suite 304
Washington, DC 20006
(202) 785-0707

OFFICERS
DONNA [illegible] POWELL
REGIONAL
REPRESENTATIVES
DAVID BROWN
SANDRA ADAMS
ALICE GONZALES
PAST PRESIDENT
CHARLES REED

July 8, 1988

Re: **Executive Summary of Federal Long Term Care Reform: A Proposal by the National Association of State Units on Aging**

Dear Colleague,

Meeting the long term care needs of a rapidly aging population is one of the greatest challenges facing the nation. Our current approach, which relies primarily on care provided in institutions and which impoverishes older people and their families, fails to provide care in the setting most preferred by older consumers - in their own homes. As designers and administrators of state community based long term care programs, our membership hopes to make a unique contribution to the national debate on how to improve our current policies. While the state programs we have developed serve a small portion of the individuals in need of assistance, our experiences in program implementation offer some useful lessons which we have translated to the design of a proposed new federal policy initiative.

In September of 1987 NASUA developed a broad policy statement which articulates the central principles that we believe should guide the development of federal long term care policy. This statement, entitled "Ending the Institutional Bias: A Call for Radical Restructuring of the Long Term Care System," emphasizes the need to reverse the current federal investment in institutional long term care services by providing the first federal dollar of coverage for home and community based care. By supporting the expansion of community care options, federal policy can create a more balanced approach to long term care resource allocation - one that is more responsive to the preferences of frail older people to receive care in the familiar surroundings of their own homes.

At the Association's 1988 Annual Membership Meeting in June, NASUA adopted the enclosed proposal which calls for a comprehensive federal legislative package of new benefits for long term care within a new Medicare Part C. This approach is based on a social insurance model, providing for universal participation of all Medicare enrollees. Funds to support this program will be generated by three major sources: beneficiary premiums, consumer co-payments and revenues generated through the Medicare payroll tax (primarily raised by lifting the $45,000 ceiling on taxable income). Beneficiaries who have functional impairments preventing them from carrying out normal activities of daily

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Our proposal recognizes the need for measures to control overall program costs. Therefore, in addition to separating service authorization from service delivery, we also propose setting ceilings on the total cost of individual care plans; limiting eligibility to persons with significant functional impairments; requiring consumers to share in the cost of their care; and controlling provider rates.

Functionally impaired persons will have access to a comprehensive home and community based care benefit and a more limited short term nursing home benefit. To control overall program expenditures, the cost of an individual's home and community based care benefit would be limited to 75 percent of the annual cost of care in a skilled nursing facility. Services comprising the benefit package would be individually tailored to respond to the specialized needs of consumers, encompassing a broad range of support services. Our experience indicates that such an approach can enhance consumer choice within the context of an affordable, cost effective program as long as a ceiling is placed on the total cost of care. The nursing home benefit is limited to 100 days of care annually in any given calendar year for all admissions. This short term coverage is designed to encourage active discharge planning beginning at the time of admission to the nursing home and to help preserve consumer resources so that return to the community is feasible.

At the local level, state designated case management agencies will have a central role in program administration. Responsibilities include assessing individual consumer needs for long term care; developing plans of care; specifying the amount and scope of services to which an individual is entitled; and monitoring the provision of care on an ongoing basis to ensure that needed services are actually provided. To maintain a cost effective program it is imperative that case management agencies, rather than individual service providers, be responsible for determining the amount and type of services that will be authorized for individual care plans to avoid any financial conflict of interest.

State governments must play a strong role in the administration of this new benefit program. By assigning management responsibility to states, this new program will build upon the long term care systems development work already underway; will significantly reduce start-up costs; and will enhance integration with existing programs. State administration will also enhance program accountability to consumers and to publicly elected officials at all levels of government. Within broad federal parameters, state responsibilities will include ensuring consumer involvement in system design and individual care

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planning, designating case management agencies, defining standards for care plan development, assuring availability of a full array of home and community based services, monitoring quality and assuring the availability of trained providers.

We recognize that viable service systems do not presently exist in some parts of the country to deliver the benefits established by this new program. However, the program structure proposed is similar to successful systems currently operating in a number of states. We believe that an adequate amount of federal financing will stimulate the creation of such systems, will preserve a role for private supplemental insurance and will help to create a balance in the choices available to older persons in need of long term care assistance.

Sincerely,

Wilda Ferguson

Wilda Ferguson
President

Sincerely,

Dan Quirk

Daniel Quirk
Executive Director

NATIONAL
ASSOCIATION
OF STATE UNITS
ON AGING

NASUA

2033 K Street, NW
Suite 304
Washington, DC 20006
(202) 785-0707

NATIONAL ASSOCIATION OF STATE UNITS ON AGING

The **NATIONAL ASSOCIATION OF STATE UNITS ON AGING**, founded in 1964, is a national public interest organization dedicated to providing general and specialized information, technical assistance and professional development support to State Units on Aging. The membership of the Association is comprised of the 57 state and territorial government units charged with advancing the social and economic agendas of older persons in their respective states. NASUA is the articulating force at the national level through which the State Units on Aging join together to promote social policy responsive to the needs of an aging America.

FEDERAL LONG TERM CARE REFORM:

A PROPOSAL

BY THE

NATIONAL ASSOCIATION OF STATE UNITS ON AGING

Adopted

June 10, 1988

NASUA Membership Meeting

FEDERAL LONG TERM CARE REFORM:
A PROPOSAL BY THE NATIONAL ASSOCIATION OF STATE UNITS ON AGING

The issue of long term care is currently the subject of considerable debate at the national level. Several options for improving the financing of long term care have been proposed, ranging from modest attempts to encourage private financing mechanisms to full federal coverage of all long term care. As architects and administrators of state community based long term care programs for the elderly, the NASUA membership is uniquely able to propose new federal initiatives by drawing upon their experiences in developing the community care systems already in place.

One of the major problems confronting persons needing long term care is the institutional bias in the current system. Because of the lack of meaningful federal funding for home care, nursing homes are currently the principle providers of long term care for persons who do not have spouses or other family members able to provide all the necessary assistance. Nursing home costs are a devastating expense to families. Medicaid requires impoverishment of its beneficiaries. In addition, Medicaid nursing home costs are driving state budgets into a squeeze which will affect quality of care.

States that have undertaken efforts to create home and community based long term care services know that individuals with serious disabilities can be served in a variety of settings. State community care systems are meeting individual long term care needs at lower costs than nursing homes, with a high level of consumer satisfaction. Unfortunately, it is too difficult to use federal financial participation under Medicaid to meet all the demand for community care, and far too many elderly are barred by means testing from using these programs.

This paper outlines a proposal for federal long term care legislation that would build on the systems in which most states already have a major investment. The proposal uses as its beginning point the principles adopted by the Board of Directors of the National Association of State Units on Aging (NASUA), including:

- In the face of the rapidly growing population of older people, especially the very old, a federal social insurance program must be the basis of long term care financing.

- The program should provide universal benefits for older persons, with a predictable, uniform long term care benefit.

- Those receiving benefits should participate in the costs of long term care services, based on their relative ability to pay.
- Administration of the program should be primarily the responsibility of states, the governmental level with the most experience in this area.
- Day-to-day management of benefits should be locally based, so differences in local service delivery systems are recognized.
- The first federal dollar of the new program should be for home and community care, to overcome the bias in current federal financing mechanisms toward institutional care.
- Covered services, regulations and standards should be family-oriented and biased toward the least intrusive home and community based assistance.
- Eligibility for receipt of benefits should be based on functional capacity, not medical diagnosis or physician prescription.
- Quality assurance mechanisms should be based on an individualized, case managed system.

Within this broad framework of policy principles, we propose a comprehensive package of federal legislation creating new benefits for long term care within a new Medicare Part C, building upon an accepted and well known program and financed through a variety of funding mechanisms. This will provide universal coverage for all Medicare enrollees. The operation of the new long term care benefit must, however, be fundamentally different from that of the current Medicare program if efficiency, cost-effectiveness and consumer satisfaction are to be assured in the delivery of these primarily non-medical services. The balance of this paper describes the components and operation of the program we propose.

PROGRAM PARTICIPANTS

NASUA's proposal addresses the long term care needs of persons eligible for Medicare coverage (persons age 65 and older and certain disabled adults). We recognize that persons of all ages and disabilities may need long term care services. In fact some state programs currently serve multiple populations and there is considerable overlap among groups -- some persons with disabilities are also older. Our expertise and program experiences, however, make us best qualified to propose program components designed for the elderly.

Therefore, while NASUA supports efforts to reform long term care services and systems that also serve younger disabled persons, this proposal focuses on services for older persons.

The full range of benefits should be universally available to all Medicare participants based on functional, not financial need. The requirement for impoverishment that is currently part of the Medicaid long term care benefit should be avoided in the new program. Any consumer cost-sharing mechanisms should be modest, with persons who are least able to pay exempted from incurring these out of pocket expenses.

BENEFIT DETERMINATION

Functional status should be the primary criterion for determining eligibility for program benefits. A comprehensive assessment shall measure a person's ability to consistently and appropriately perform essential activities of daily living (bathing, dressing, toileting, eating, transferring) based on the person's physical, cognitive and emotional/behavioral functioning and shall review health conditions that may require in-home services. An assessment finding that the person's functional disability results in the need for human assistance in performing two of the five specified activities of daily living will result in eligibility for program benefits.

The need for nursing care should be reviewed as part of the assessment process; however, service eligibility will not be dependent upon a need for health services. State experience indicates that some persons in need of long term care have limitations in performing activities of daily living and yet do not need health services. In addition, eligibility should be established without regard to the underlying condition or medical diagnosis resulting in disability; specific types of conditions which may result in impairments (e.g., developmental disability, chronic mental illness, chemical dependency) should not be excluded.

Client functional assessments will be performed by state designated case management agencies and will include a face to face interview with the individual and his or her caregiver. Standards for functional eligibility should be federally defined and uniform across states. The Secretary of DHHS, in consultation with states, will develop the protocol for determining eligibility, including the components of the assessment tool used to measure impairment levels.

States will be required to establish a process for timely resolution of appeals resulting from denial of service eligibility. In those instances where a state has upheld the initial decision of a case management agency, individuals will have the right of appeal to the federal government.

The development of written individual care plans will be based on the findings of the assessment process. In addition to measuring functional capacity for determining program eligibility, the assessment should gather current, valid and comprehensive information about the individual's health condition and her/his home and community environment to determine what services, supports or other environmental modifications would assist the person to live and participate in families and communities. States shall develop, with federal approval, the components of the assessment tool used to identify the services needed to meet the unique needs of individuals with varying disabilities, service preferences and living arrangements. This determination will be made within the context of local service delivery systems and an available local work force, both of which will vary across the country. In addition, an assessment of the adequacy of the individual's informal support system (currently existing and in the near future) will identify the more personal and informal care that family and friends are willing and able to provide and that the consumer has agreed to accept. At the same time, within the context of an entitlement program, the eligibility criteria will not require any level of assistance from families or others. While this program should build upon the informal care system already in place, older consumers should not be penalized if families are unable to provide assistance.

The state designated case management agency will develop individual care plans, specifying in some detail the type and amount of needed services. Only through the development of care plans by the case management agency will specific program benefits be authorized for individual consumers. Attending physicians and other health care professionals involved with individual consumers should be consulted during the care planning process when appropriate, but will not be required to approve those portions of care plans which primarily utilize non-medical support services.

The case management agency must take into consideration the preferences of individual consumers in designing care plans. To assure consumer acceptance, the individual (and the informal caregiver in instances where a substantial amount of care is to be provided by a family member or friend) should have final approval of the care plan. States shall be required to establish a process for timely resolution of grievances and appeals related to the decisions of the case management agency.

All case management functions, including assessment and care planning, shall be performed by an entity which is not a service provider to reduce the potential for conflict of interest. If necessary, this requirement could be waived during an initial start-up period to allow new service delivery systems to be created. Governmental agencies should also be exempt from this requirement, provided that two distinct organizational units provide case management and direct services. In addition, exemptions should be allowed for state designation of entities which accept financial risk for all long term care needs of their enrollees, and which are voluntarily chosen by beneficiaries. These entities will agree to have eligibility determination for their enrollees performed by an independent entity and will submit to ongoing oversight of their case management and service activites.

BENEFIT PACKAGES

NASUA's legislative proposal includes both a home and community based care benefit and a limited nursing home benefit.

Ideally, the specific home care services that could be supported through this new program would not be delineated in federal law, but would rather be individually tailored to respond to the needs of an older person as identified through the assessment process. A major shortcoming of the Medicare and Medicaid programs as currently designed is the lack of flexibility in the types of home care services that can be provided; available services therefore correspond to federal rules rather than to the unique needs of individuals. Under this new program, case management agencies should be able to authorize the provision of any service that assists an older person to carry out activities of daily living, maintain social integration and family supports, enhance consumer self direction, and prevent inappropriate institutionalization.

Our reluctance to delineate a specific package of allowable services grows out of three concerns: 1) This program should avoid the design mistakes of Medicare and Medicaid and encourage the development of creative responses to individual needs rather than fitting the needs of older people into rigid service categories. 2) Certain services can substitute for another, depending upon client needs and preferences and the availability of home care staff. For example, assistance in meal preparation can be addressed through personal care services, a live-in personal care attendant or home delivered meals. 3) The assistance typically needed by older persons to cope with activities of daily living are supportive services rather than medically oriented services, and such services are best described as a response to individually assessed needs. Our experiences with similar programs indicate that specifying a set of allowable services has frequently resulted in a medical model, and in turn in a service response that is less flexible and more expensive than necessary.

States should be required to assure that a broad range of services are available to enhance the independent functioning of program beneficiaries. In addition, community based long term care services should be provided in a variety of settings, including in a person's own home (on either a visiting or live-in basis); in congregate service centers such as adult day care centers that provide therapeutic programs and socialization opportunities; and in alternative living arrangements such as foster homes, board and care facilities and shared housing. However, room and board costs in community settings would not be covered by this program. To illustrate the potential array of services, the following set of services should be included within legislation as examples of allowable services: personal care, chore, adult day care, respite care, personal supervision, nursing, therapies, home health care, transportation to and from service centers, assistive devices, home and financial management, and minor home or vehicle modifications. It will be crucial to assure that the current Medicare acute benefits of skilled home nursing, therapy and home health aide services be in no way diminished.

Within the constraints of cost limits, local service supply and quality assurance, consumers (or their guardians if the individual has been adjudicated incompetent) will be able to chose the **type** of living arrangements they will have while receiving services (e.g., whether to live in group settings) and the **types** of services to be provided (e.g., whether a need for assistance with meal preparation will be met through home delivered meals or a homemaker). Again, the same services can be provided in a variety of ways. Consumers' preferences must be honored to the greatest extent possible in choosing the specific provider of services, within the limits of cost-effectiveness and quality assurance. For example, consumers should not be able to choose a provider that does not meet program standards, that has service unit costs that are significantly higher than other providers of identical services, or that is not available in the individual's community.

States should not be precluded from including individuals (not affiliated with agencies) as formal providers, so long as the individual meets federal, state or local training or other requirements and is approved by the case management agency. Such client employed provider arrangements can potentially offer consumers substantial control over the implementation of their care plans.

In order to control overall program costs, an annual limit on the per person benefit should be established for home care and tied to 75 percent of the average Medicare rate for skilled nursing facility care in the state. This provision also ties increases in the cost limit for the per person home care benefit package to increases in the average Medicare rate for skilled nursing facilities.

Several explicit exclusions from the payment cap will be important. First, acute care benefits received during an episode of illness and currently covered under Medicare should be excluded. Second, the costs of assessments, care planning, ongoing case management and service monitoring should not be included. Case management is an important process for utilization control, cost-containment and quality assurance, but should not be applied to the limit on personal services. Instead, case management costs should be reimbursed on a capitated cost per client, with such rates varied to reflect differences in local wages while responding to federal expectations about minimum client and provider contact, as well as maximum reasonable average time spent per client.

NASUA believes that the primary emphasis of any new federally financed long term care program should be on expanding the availability of home and community based care. Consumers overwhelmingly prefer to remain in their own homes and communities to receive needed care. A number of states have proven that community care can be provided for consumers needing the same level of care as those who enter nursing homes and that on average, it is less expensive to do so. Yet the ease of arranging for all needed care through placement in a nursing home creates incentives for families and care managers (hospital discharge planners, physicians, etc.) to opt for nursing home care instead of packaging community based arrangements. At the same time, we recognize that at some point in their lives, older people may have needs that can only be met through nursing home care.

In many parts of the country, the long term care system is significantly out of balance, with institutional capacity and expenditures far outstripping those on the home and community side. A major new federal entitlement to long term nursing home care, absent the current utilization disincentives resulting from Medicaid income and asset limits, would result in a rapid growth in nursing homes and related costs.

Reflecting these concerns, NASUA proposes that the benefit package cover nursing home care beginning with the day of admission and be limited to 100 days in a given calendar year for all admissions. Consumers will make no co-payment for the first 20 days and a 20 percent co-payment for the remaining 80 days. Medicaid would cover the consumer share for eligible persons. This short term coverage is designed to encourage active discharge planning beginning at the time of admission and help preserve consumer resources so that return to the community is feasible following a short term nursing home stay. The case management agency will authorize access to both the nursing home benefit and the home and community care benefit.

The proposed benefit replaces the current Medicare nursing home benefit, covers either SNF or ICF care, assumes implementation of the spousal impoverishment provisions of the Medicare Catastrophic Coverage Act, and allows for a potential role for private long term care insurance. In addition this benefit recognizes that over one half of all nursing home stays are for less than 100 days.

PROGRAM MANAGEMENT

States must play a strong role in the administration of this new benefit program. By assigning states management responsibility, this new program will build upon the long term care systems development work already underway, significantly reduce start-up costs, and enhance integration with existing programs. Within broad federal parameters, states will:

- designate and certify case management agencies;
- define standards for care plan development;
- assure availability of a full array of home and community based services;
- develop or direct the local development of contracts with qualified providers to participate in the program;
- define allowable provider costs;
- develop provider reimbursement systems; and
- monitor quality and train providers.

These responsibilities can be exercised within a framework of federal regulations, while at the same time reflecting the experience and expectations of state and local officials and consumers themselves. Administrative costs of the state shall be covered primarily by federal financing with some state financial participation.

Fiscal intermediaries would have a role only to the extent that states choose to contract for purely administrative functions. Fiscal intermediaries would not be empowered to second-guess decisions of case managers, as they do with current Medicare providers. Rather, their role would be to perform the mechanical tasks of billings and claims processing and to produce whatever data reports are contracted for by the state to meet state or federal requirements.

State certified case management agencies will conduct individual functional assessments, certify consumer eligibility for benefits, develop care plans specifying the amount, type and duration of program benefits, authorize the delivery of services and monitor, on an ongoing basis, the implementation of care plans. Case managers will be paid for these activities on a capitated basis. Case management agencies may contract directly with service providers to the extent authorized by the state.

QUALITY ASSURANCE

States should be required to develop mechanisms to assure the provision of quality care for both home and community based care and nursing home care. Standards for nursing home care are incorporated in the Nursing Home Reform Act of 1987. Standards for most home and community based services should not reflect typical medical model criteria (such as professional provider credentials) that are likely to increase costs unnecessarily. Instead quality assurance mechanisms should focus on achieving maximum consumer functioning and reflect consumer preferences. By using a managed care approach, case managers will, on an ongoing basis, monitor the implementation of individual care plans to make sure that beneficiaries receive assistance appropriate to their needs and preferences. In addition states must assure that:

- Assessments and care plans are completed and service delivery initiated within a reasonable time period after consumer contact with the case management agency.
- An appeal mechanism exists to consider grievances on eligibility determination, amount, type and duration of services authorized in care plans, and the manner in which services are provided.
- Providers comply with requirements for state certification and with relevant employment laws including those related to minimum wage and payment into social security and unemployment compensation funds.
- Providers have a demonstrated capacity to deliver services.
- A mechanism will be established to receive and investigate complaints.
- A state advisory committee whose membership reflects a balance of consumers and other interested parties will be established to provide input on all aspects of program design, with particular emphasis on mechanisms to assure quality care.

The federal government will also establish sanctions to be taken against states found to be out of compliance with minimum program standards and will assist states in enforcing sanctions against local case management agencies or direct service providers.

FINANCING

Funds to support this program will be generated by three major sources: beneficiary premiums, consumer co-payments and revenues generated through the Medicare payroll tax (primarily raised by lifting the $45,000 ceiling on taxable income). The premium amount should vary by individual income and could be collected in part through the federal income tax system, and in part collected in the same manner as other Medicare premiums.

For the home and community based care benefit, beneficiary cost sharing would be equal to 30 percent of total program cost. A 20 percent consumer co-payment would be required for services actually received, with the balance of the total beneficiary cost sharing amount collected through premiums. All Medicare beneficiaries will participate in the program. For the nursing home component the program covers 100 percent of the cost of nursing home care for the first 20 days and 80 percent of the cost for the remaining 80 days; consumers pay the balance. Premiums and co-payments for home and community care and nursing home care will be paid by Medicaid for persons with incomes below the federal poverty level.

NASUA recognizes that with the initiation of this new program, some state expenditures for home and community based care and nursing home care which were previously incurred through state general revenue supported programs and as state match for Medicaid will no longer be required due to these new federally financed benefits. Federal policymakers will likely seek provisions that retain some state financial participation in these new benefits. While we understand this concern, NASUA is not in a position to make a concrete proposal to address this issue. We do believe, however, that some of the state cost savings should be used to pay for the consumer cost sharing amounts for low income persons, financed through state and federal Medicaid funds.

Adopted June 10, 1988
NASUA Membership Meeting

ENDING THE INSTITUTIONAL BIAS:
A CALL FOR RADICAL RESTRUCTURING
OF THE
LONG TERM CARE SYSTEM

Adopted

September 18, 1987

NASUA Board of Directors

ENDING THE INSTITUTIONAL BIAS: A CALL FOR RADICAL RESTRUCTURING OF THE LONG TERM CARE SYSTEM

NASUA recognizes that states have moved aggressively to redesign local delivery systems and funding structures to respond to the chronic, long term care needs of older Americans, but believes that further progress is hindered by the absence of a permanent and comprehensive federal long term care policy for financing needed services.

As the public agencies charged with determining the needs and preferences of the nation's older citizens, state units on aging, as well as sub-state area agencies on aging, are acutely aware of the overriding fears expressed by older persons and their families regarding the risks associated with a need for long term care in this country. Once expressed somewhat vaguely as a fear of "losing independence," the concerns of increasingly knowledgeable older consumers have become focused on the stark realities of long term care in America: likely separation from home and familiar persons, the inevitability of pauperization, and the possibility of inadequate services or poor quality of care. Regrettably, the concerns are well-founded.

The dangerous inadequacies of long term care in America are built into the structure of the long term care system, whose foundation was laid in 1965 when Medicare and Medicaid were created as social insurance for elderly and poor people, through legislation drafted without knowledge or experience with long term care needs of long-lived Americans.

One quarter of the nation's elders are likely to experience multiple disabling conditions which render them dependent on others for long periods of time. Yet our nation's health insurance programs have been unable to assist older persons and their families to cope with this reality.

The cost of long term care is inescapable. The fastest growing segment of the population is the very oldest. By 2030, the public cost of long term care will be four times higher in current dollars. What we purchase at enormous public and private cost is a patchwork of care which too often fails to meet the minimum expectations of payor, provider and consumer.

The predominant and preferred focus of long term support is in the home. Yet government programs are structured to give most care in the most intensive and restrictive manner, in institutional settings, regardless of the necessity. The bias toward institutional care in federal financing is so rigid that complicated and unwieldy "waiver" programs have had to be introduced to enable states to divert a modest level of resources toward the real long term care setting - the home.

Medicare is a universal insurance program for the elderly (with substantial participation in costs by the beneficiaries) which does not pay for the major catastrophic cost of the elderly - long term care. Over its history, Medicare has rigidified the division between acute and chronic care. Because of its acute care focus, Medicare reinforces the medical model of care: physician - dominated, nurse provided, in institutional or clinical settings.

Yet long term disability is a social problem, a functional problem, a family problem. Medical and institutional care ought to be a support to a long term care system, not the driving force. Regrettably, the Medicare system has not addressed this issue but has instituted procedures which shift the problems and the costs from the federal financed health care system into the state and privately financed long term care support system.

State systems of long term care were necessarily built on Medicaid in order to capture federal financial participation. The institutional bias in state long term care programs is overwhelmingly evident. Medicaid has become the nation's long term care insurance program. But the Medicaid long term care system exacts a terrible price for its benefits: it requires pauperization to gain access; it requires the dissolution of households and relocation to institutions; it is organized through the medical care provider systems; and it is not uniform in its benefits. The Older Americans Act is the only piece of federal legislation that promotes comprehensive, coordinated systems of community care, but it fails to provide the authority or financing to fulfill its mission.

Despite these handicaps, states have moved agressively in the last decade to organize and rationalize long term care systems, by coordinating, financing and designing systems which more closely meet the needs and preferences of their older citizens. States have discovered that Medicaid and other federal funds are not the stable and predictable source of funding which can facilitate long range planning by states or individuals. Furthermore, federal organization of these programs encourages fragmentation, hinders state coordination and reinforces the predominance of institutional care.

Nevertheless, states have taken deliberate action to:

1) Reorganize and coordinate state level efforts;

2) Reorganize local delivery systems to do assessment, case planning and case management;

3) Constrain the growth in nursing homes and divert savings to community care;

4) Develop new financing mechanisms through Medicaid plans, waivers and state revenues;

5) Investigate private insurance;

6) Develop new services;

7) Define and target the most vulnerable;

8) Develop equitable cost sharing methods for participants; and

9) Pursue standards of quality and productivity based on individually assessed consumer needs and preferences.

These efforts have resulted in a vastly improved array of service options, increased involvement of family and community in care systems, and a more judicious management of resources, but only for a segment of the population requiring care. Current structuring and financing of long term care is not adequate to meet the current need, much less the future growth in the long term care population.

The solution so urgently and immediately needed is a social insurance plan which provides a predictable, uniform long term care benefit level which older people, their families, state and local governments, private insurers and providers can plan on. Knowing what federal insurance is committed to provide will enable these other actors in the system to anticipate and plan for the additional resources and services which will be required.

The system older persons deserve will be most equitable and responsive to their individual needs if it is federally-financed, state-administered, locally- managed, and family-oriented.

Federal long term care insurance should provide its first dollar of benefit in home and community care which is the least disruptive, least restrictive and most preferred care, building as it does on supportive family and neighborhood relationships. The benefits of long term care insurance should be universal and predictable for all older individuals, with uniform cost-sharing based on the ability pay. Benefits should be tied not to diagnosis or physician fiat but to persons who are impaired to a degree that they require continuous, reliable long term support to maintain their most ordinary human functions. Regulations and standards should be biased toward the least intrusive, home and community based assistance.

Quality assurance needs to be built on an individualized, case-managed system which monitors for achievement of the outcomes sought by the consumer: comfort, security, dignity.

The state role in a restructured long term care system should not be disregarded. States have made a substantial investment in long term care. States have the principle regulatory role. States comprehend the balance of social and medical need. States are responsive to and accountable for the needs and preferences of local citizens.

The role the states' aging network may play in long term care will vary according to structure and custom. But across the country, it is the aging network which must involve older persons and their families in expressing their values and preferences about the principles, benefits and organization of the long term care system.

NASUA recognizes the complexity of this undertaking and the need for partnerships among a wide and diverse group of organizations and agencies to quickly advance these goals as a crucial national priority. NASUA commits itself to this important partnership in meeting the challenges of developing national and state strategies to address the chronic care needs of our rapidly aging population.

Adopted September 18, 1987
NASUA Board of Directors

Chairman **Rockefeller**. Incredible timing. Mildred, you were discussing a waiver program that Senator Moynihan tried to get included in reconciliation.

Ms. **Shapiro**. Senator, it was my understanding that the Senate Finance Committee did report out. It was not reported out in the form in which it was originally introduced, but it turned out to be a New York demonstration. It was my understanding that that was reported out Tuesday night. I may be misinformed.

Chairman **Rockefeller**. If it was reported out of the Finance Committee, I think it may have been a substantially scaled-back version.

Ms. **Shapiro**. That's right. It was done only for New York. All the other States will need it, correct.

Chairman **Rockefeller**. In your testimony, you describe a program which is very different from existing Medicaid Programs. The Medicaid Program, as you indicated, has huge shortcomings and meets the needs of less than half of those individuals under the Federal poverty level.

Are you proposing major changes in the Medicaid Program, and if so, how do you make sure that the needs of the poor are met?

Ms. **Shapiro**. Well, we're proposing this as cost saving to the States so that money which is currently being spent to subsidize the middle class who could otherwise afford insurance will be redirected. We have the potential of saving down the line hundreds of millions of dollars over maybe the next decade. That money could be channeled to reach more of the poor. Right now, States are reluctant to increase income eligibility levels because they are spending so much on long-term care.

Some of it is deservedly for people who really are and have been low income. But we know there are many people out there who really could afford to buy insurance.

Chairman **Rockefeller**. You heard Dick Schweiker talk about $4 trillion in the system that could be used for long-term care, what was your reaction to what he was talking about?

Ms. **Shapiro**. I think that's an opportunity. The conversion of a lot of financial instruments—there is some tax owed if you convert pensions or life insurance to use for long-term care.

I understood what he was saying. You would just get your money in advance. They're doing that for life insurance policies for people who have AIDS, for instance. They allow them to take the money in advance because they need it for long-term care and it won't be much good when they're dead.

Chairman **Rockefeller**. When you get your money in advance, doesn't there have to be a lot of front-end loading, thus higher premiums?

Ms. **Shapiro**. I would rather you ask that question of an actuary.

Chairman **Rockefeller**. OK. A lot of what we have heard today seemed to suggest that long-term care, and I ask this of both of you, is a problem of the elderly. It isn't just the elderly who need long-term care. At our last hearing we heard about people who are lost in between because they couldn't get health insurance and can't get help when they need long-term care. I was called by a friend of mine to see if I could get help at NIH for his child in Texas who is 14 years old and suffering from Alzheimers.

People of all ages have long-term care needs. Is what both of you are talking about include long-term care needs of the nonelderly?

Ms. **Shapiro**. I think it has to be done in stages. I think the price tags are so high that to try and do it all at once may be a problem. We were suggesting that it start with the 65-and-over, and then probably phase in because there are needs for people under the age of 65.

We have other programs, the so-called Katie Beckett amendment, if you remember that, our care at home program where we do not deem the income of the parents to the child so that children don't have to be treated in hospitals in order to get Medicaid eligibility.

Chairman **Rockefeller**. How can we make the value judgment that the elderly should be taken care of before the needs of children. I don't understand it.

Does one make a public policy value judgment? In other words, when one thinks of seniors, it is a very clear image. Everybody understands that and the associations that lobby on behalf of those groups are certainly on the minds of people, especially in Congress.

When one thinks of somebody who has got Alzheimers disease at the age of 42, and we heard from a family in that situation at our last meeting, or of the 14-year-old boy or of the disabled, somebody who is going to need long-term care all throughout his life and is very young, that doesn't fit the image of someone needing long-term care.

So then, you worry about how you make these value judgments. You say, well, of course, we're going to start with seniors. We can't afford to do it all. Is that a fair value judgment for public policymakers?

Ms. **Shapiro**. Well, when you work in the Medicaid Program you do see all of those other cases that fall into the category of the disabled—brain trauma, spinal injuries, motorcycle and auto accidents, children born with all kinds of anomalies. We do see it all. Many of them get covered through SSI disability and Medicaid which they would get automatically if they have a severe disability and are financially eligible for SSI.

Ms. **Justice**. I think, Senator, that some of the delivery systems I described can be applied not only to the elderly but to the developmentally disabled and other population groups—the adult physically handicapped, for example. Some States have parallel delivery systems for these populations.

In the final analysis none of the delivery systems covering the developmentally disabled or the physically handicapped or the elderly are sufficiently funded to meet the needs at this time.

Chairman **Rockefeller**. Let me come back to the Medicaid point. Medicaid, obviously, doesn't affect a lot of income groups. I wish you could have been at our last hearing—yes, you do see all those people, but they are Medicaid people, Medicaid kids, Medicaid young people.

What you don't see are the people who don't qualify for Medicaid on an income basis but who cannot go out and buy insurance on their own. Those are some of the people that we're talking about. So, in your plan Mildred and Diane, if you care to reflect on it, how do we reach those people?

Dick Schweiker is saying we can do it through a $4 trillion reserve we have, whatever it is, if we just change the law. I hope he's right. He may be right. That may be an incredible contribution to what we've been learning here. What about all of the nonelderly in these middle groups that when you see them you say to yourself, gee, I didn't realize there were that many people out there.

Ms. **Shapiro**. If you rely on the private sector, you will always have gaps in coverage. That is one of the advantages of a universal Government program. There's no question about that.

Chairman **Rockefeller**. Would you agree with that Diane? Is it absolutely inevitable that the only way people who need long-term care can receive it is through a public program? Congress and Americans in general like to get easy solutions.

That was one of the problems with catastrophic. If you stitch things together, they may very well work, but the conventional wisdom is that sometimes stitching is dangerous and doesn't work.

The other side of that is that stitching may be the only option if, as I think you indicated, the political realities of universal coverage would be fairly difficult at this time and we've got to propose something that not only works—and our charter says it has got to work for everybody, but it also has to be able to pass the Congress.

Ms. **Shapiro**. It has to be doable and affordable.

Chairman **Rockefeller**. So, what's wrong with stitching? What's wrong with some stitching? You jumped from your plan to universal.

Ms. **Shapiro**. You kind of forced me into that. You asked me what——

Chairman **Rockefeller**. Well, I sort of did. Then undo me. Stitch me correctly.

Ms. **Shapiro**. OK. I'm proposing that what we do we do incrementally. That we test things on a small testing ground. I don't believe in making mistakes coast to coast as we sometimes do. I'd rather do it in a small way, and debug it and learn. There is so much to learn. Long-term care insurance is not health insurance. It's different and there are different kinds of needs and services.

I'm proposing that we start things on a pilot basis and learn from it. There won't be modest costs; and there will be savings for the Government. What we learn from that ultimately can be expanded and utilized in a broad social insurance program when we find out how we want to finance it.

Chairman **Rockefeller**. Diane?

Ms. **Justice**. It seems to me that some nonelderly populations in need of long-term care services such as children and the developmentally disabled, would not be served by a private approach because they would not, in essence, be insurable. Their needs for long-term care would be present at a very young age; therefore they will not be a population that will benefit from a private insurance approach that relies on the creation of a risk pool of persons who might at some future time need long-term care. Therefore, they would be best served by a social insurance program.

Chairman **Rockefeller**. It is interesting that in this whole question of how you pay for things—and since I was a Governor for 8 years I understand that States can't pay much more.

Oddly enough, States are sometimes more imaginative than we are in Congress. We are all reading the President's lips and not raising taxes, and you find Democrats now who want to join into that because everybody is fed up with taxes, so Congress has its own way of saying we're not going to raise taxes President Bush. If you're not going to raise taxes, we're not going to raise taxes.

What I'm trying to get at is, do you think States really have run out of resources for long-term care, specifically for Medicaid? Are States really pushed to the limit?

Ms. **Shapiro**. Many of the States now have deficits. Last year and this year, New York had huge deficits. Frankly, when Medicare catastrophic coverage is repealed, what Congress has left in are those things that will cost us more money, like mandating expanded Medicaid coverage for pregnant women and children. And everything that Congress is going to repeal—well over $100 million in savings will be lost on just the nursing home benefit alone.

So, we're left with new costs, a deficit, and no savings. I think it's going to be very difficult to have any new mandates, though I must say that our Governor was one of two who refused to sign a letter from the Governors requesting no more mandated Medicaid benefits.

Chairman **Rockefeller**. Diane?

Ms. **Justice**. I think States are in a difficult spot. Program administrators in those States that have been out front in expanding programs have expressed to me their concern that Governors and State legislators have allocated about as much money as they can at this point to long-term care services. These State officials are also concerned about being able to continue the financial commitments they have already made in light of other demands placed on State budgets.

There are also a number of States that I have not talked about that have not done very much due to these financial constraints. I have talked about the States with resources to move ahead. Not all States have initiated programs like the ones I described.

Chairman **Rockefeller**. Alabama, for example. Do you think Alabama ought to be allowed to have such strict income eligibility under their Medicaid Program?

Ms. **Justice**. To help all States use Medicaid better the Federal Government needs to provide States with more program flexibility. For example, the waiver programs have been a useful vehicle for States in expanding the availability of long-term care services; however, as the programs have evolved over the last 7 or 8 years, we have seen increased restrictions that make it more difficult for States to be able to take advantage of those waiver opportunities.

It is particularly interesting to look at Medicaid waiver programs since by their very nature, these programs represent a financial partnership between the Federal Government and State governments. In the short term, trying to loosen some of the restrictions that prevent rational programs under waivers would be a big help.

Chairman **Rockefeller**. If States had a choice, let's say, between financing acute care or long-term care, or contributing more to either of them, which would you two choose? What would Uncle Nelson have done?

Ms. **Shapiro**. Well, if it's life threatening you always go for coverage. Acute conditions could be life threatening. You always take care of life threatening conditions first, no options. That's a conundrum. I think you have to spread the risk where there is ability to pay, and that's how I get of answering your question. I think for those who can, they should, and for those who can't, Government should be there.

Chairman **Rockefeller**. That's worked wonderfully on catastrophic, hasn't it?

Ms. **Shapiro**. Life is not fair, you've heard that before.

Ms. **Justice**. I am clearly a long-term care advocate, so I would hope that States would spend more money on long-term care if they had resources to use. There is more Federal coverage for acute care services for the elderly. For example, Medicare's primary focus is on acute care, so States have tried to develop programs that fill in the gaps in the existing Federal financing. Those gaps have primarily been in long-term care.

Ms. **Shapiro**. The problem is there is no real third-party payor for long-term care except Medicaid. There is just a pittance—what is out there is just a beginning, not even an infancy of the long-term care insurance industry yet. It's just starting. What you have is Medicaid as really the only payor out there for long-term care. It forces people into those difficult positions.

Chairman **Rockefeller**. An earlier witness, I'll pose this to both of you and then we'll call this to a close, said that insurance companies insure only manageable risks, avoid ambiguous risks, and control induced demand. Do either or both of you agree with that?

Ms. **Justice**. I agree. At this point, experience with private long-term care insurance is very limited. The industry is approaching this area very cautiously because they, like the rest of us, do not really know what to expect in terms of cost.

I think that all of those problems that you have laid out, in fact, exist in most long-term care policies.

Chairman **Rockefeller**. Mildred?

Ms. **Shapiro**. Well, I think while insurance companies are in the business of insuring risks, they often are risk avoiders. I think those insurers that would participate with us in a partnership would have to meet very high standards or they could not use that stamp of approval and be able to sell the fact that after the consumer exhausts their policy, the State would continue to provide coverage and offer a State guarantee.

To do that, we will set very high standards. We expect we will have a small number of high quality companies and products to sell, and the others would not participate.

Chairman **Rockefeller**. We'd have quite a lot of discussion around here if we tried to set standards for insurance companies, wouldn't we? You're suggesting that they may be part of what has to happen.

Ms. **Shapiro**. That's what has to happen.

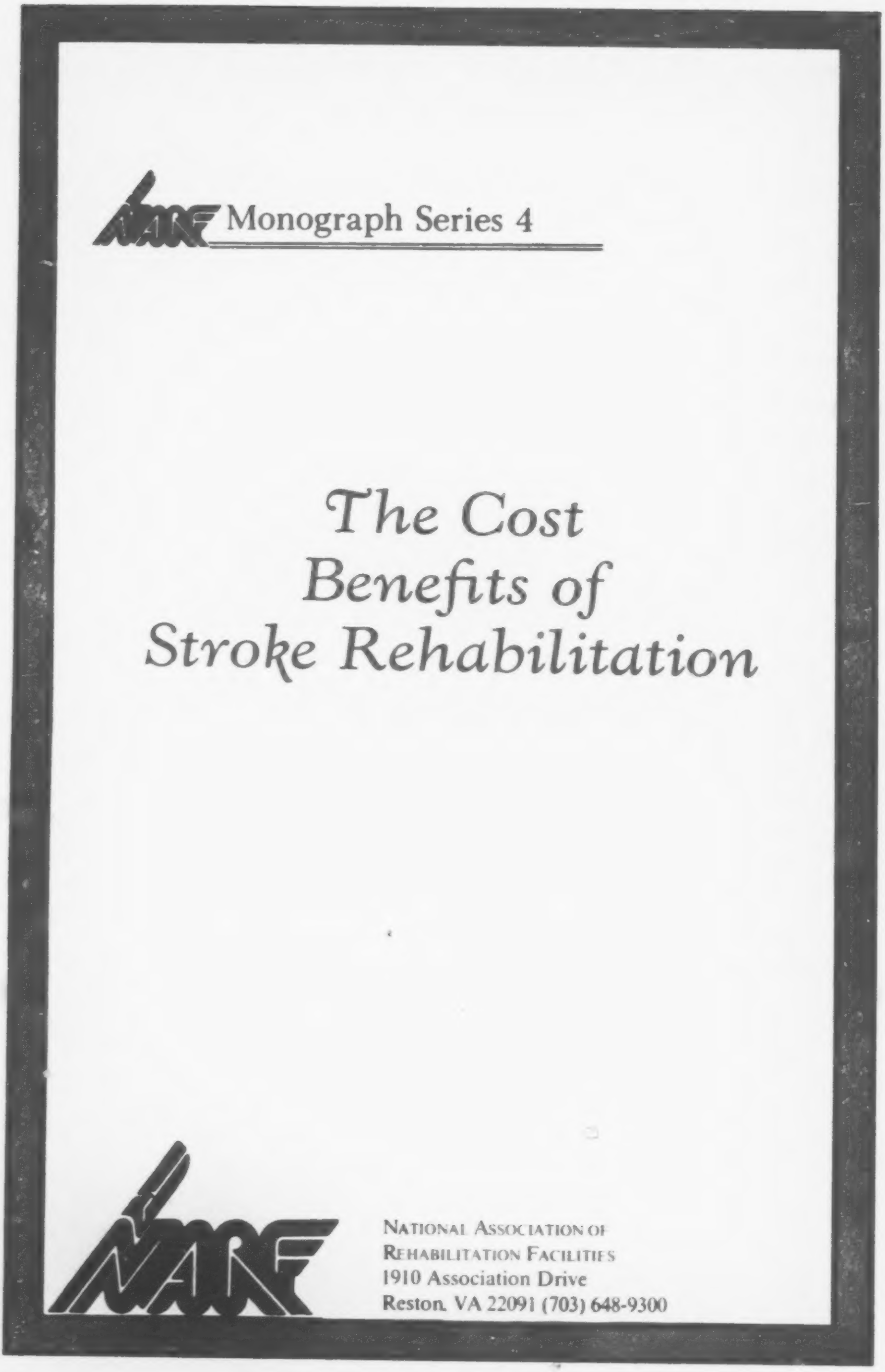
Chairman **Rockefeller**. You said it, Mildred.

Ms. **Shapiro**. I said it.

Chairman **Rockefeller**. On that note, I thank both of you very, very much, and thank everybody for attending this second hearing. The next one will be on October 24.

[Whereupon, at 1 p.m., the hearing was adjourned.]

APPENDIX



NARF Monograph Series 4

The Cost Benefits of Stroke Rehabilitation

NATIONAL ASSOCIATION OF
REHABILITATION FACILITIES
1910 Association Drive
Reston, VA 22091 (703) 648-9300

The Cost Benefits of Stroke Rehabilitation

Dale E. Eazell
President

and

Mark V. Johnston
Research Associate

Casa Colina Hospital for Rehabilitative Medicine
Pomona, California

National Association of Rehabilitation Facilities
1910 Association Drive
Reston, VA 22091 (703) 648-9300

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FOREWORD

Rapidly increasing costs in all areas of the health care delivery system have mandated that providers justify their services for effectiveness and efficiency. Cost benefit analysis is a logical step for society to compare the financial benefit of alternative delivery systems and, in fact, raise the question of whether certain services and programs are financially justifiable under any circumstances. In rehabilitation there is a limited amount of such data available and what is available, is scattered and difficult to retreive.

Medical rehabilitation is a highly specialized area of medicine the structure, format and benefits of which are not well understood by the public, the majority of other medical providers or the third party reimbursement system. Mr. Eazell and Mr. Johnston have made a major contribution toward furthering understanding of the benefits of rehabilitation for a major diagnostic category— stroke— which has tremendous impact on the financial, social and emotional aspect of the lives of millions of Americans.

The NARF Monograph Series is designed to enhance the understanding of rehabilitation among the general public and a variety of special interest groups. The contribution of Eazell and Johnston in advancing that objective is appreciated.

JAMES A. COX, JR.
Executive Director
National Association of Rehabilitation Facilities

THE COST BENEFITS OF STROKE REHABILITATION

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INTRODUCTION

Although advances in rehabilitation and treatment for stroke patients have occurred at a rapid rate in recent years, most of these patients are still being denied the full benefits of this accrued knowledge. By hundreds of thousands they wait out their post-stroke years languishing in nursing homes and hospitals, or at home, often unable to walk, talk or even care for their basic daily needs.

Why is this permitted? With proper rehabilitation, many could return to self-sufficiency and an active, productive life.

Some may argue that it costs too much to rehabilitate stroke patients. Experience, however, proves just the opposite—and it is dramatically documented in the following pages.

This paper is based on a massive literature search exploring the cost benefits of rehabilitating stroke patients. Augmenting the study were interviews with leading experts in the field.

The humanitarian benefits of stroke rehabilitation of course reach far beyond even the impressive cost savings—ranging conservatively from $740 million to $1.18 billion annually [1] —which can be achieved by proper rehabilitation.

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[1] Unless otherwise stated, all cost figures in this paper have been inflated to mid- to late- 1980 levels as follows: the Consumer Price Index for medical or general goods was used to inflate prices to the May, 1979 level; the 1980 level is estimated on the basis of an additional 15% general inflation rate. Expenditures for any specific year (e.g., 1975) are expressed in terms of that year's prices.

THE PICTURE IN BRIEF

A sudden burst of devastating pain to the head. And then . . . nothing. A forced retreat into darkness.

Later, consciousness returns, and with it awareness—but awareness only to a limited degree. Yes, seeing is possible. Hearing is possible. Even thinking, although perhaps confused at first, is possible. But the body will not respond to its master, for the brain is in a state that may be likened to shell-shock: it is simply unable to function. The words of terror and outrage will not come, the arms will not rise to shake their fists in protest, the legs will not move to propel the body away from this terrifying episode. The mouth will not open nor the jaws work to permit life-sustaining nourishment.

This is a stroke—an interruption of the vital blood-flow to the brain by either a clogged or burst artery. And it happens to Americans at the alarming rate of nearly one per minute, every minute of every year—for a total in excess of 414,000 new stroke cases reported annually.

Although more likely to strike older people, stroke knows no age barriers. Babies can be born with it, toddlers to teens can be afflicted, young adults and middle-aged people can be cut down in the prime of life, the elderly can fall victim to its fury. There is no sure defense against its onset. It is America's third major killer—second only to heart disease and cancer—and this speaks chillingly of its pervasiveness.

Of the 414,000 new cases reported in a given year, 183,000 will die from the stroke's intensity. What happens to the other 231,000 victims?

A good question. The prognosis depends on the severity of the stroke and whether the victim has access to rehabilitation services—or whether he sits and vegetates, painfully and slowly, for the rest of his life.

If the latter, if the course of rehabilitation is not elected, the hapless stroke victim can end up costing the American economy $17,000 per year in nursing home costs—or in excess of $119,000 over the course of his expected lifetime. Not to mention the grief, misery and poor health that will ravage the victim and his family for all those long years.

Multiply this $17,000 annual cost by the number of new stroke victims reported but not rehabilitated each year, and America finds itself footing a bill of over one billion dollars for its failure to make rehabilitation available to stroke victims. Add to this figure the "old" (struck down in previous years) victims carried over from earlier years and you have a truly staggering sum that is being paid to care for stroke victims.

Although compelling, these dollar amounts cannot begin to tell the full story of what lack of rehabilitation means to a stroke victim and his family. What is all this money buying? Happiness? Comfort? A meaningful, worthwhile life? Unfortunately the answer is "none of the above." Other than basic care necessary for mere existence, these billions of dollars are buying mostly misery.

Let's look in on the daily world of a typical non-rehabilitated stroke victim, whose care is costing the economy such a high sum. Entering a nursing home, we find him over there in that corner. He's the sad-looking gentleman, strapped to his wheelchair, staring out with uncomprehending eyes, passing the days with an agony of soul, hoping for—yet fearing—release by death from the hell into which his life has been plunged.

Not having received rehabilitation, he cannot walk or even go where he wants in his wheelchair. He cannot dress himself, or perhaps even feed himself—never mind return to work—for occupational and physical therapists have not taught him that he can do these things with his remaining powers. Without rehabilitation medicine and nursing, he remains incontinent, subject to needless infetions or painful contractures. What is more, he has lost much of his previous powers of speech. So he cannot communicate his thoughts, his need to go to the bathroom, his thirst or what causes him pain. He is at the mercy of others.

All he can do is sit, think and suffer. He gives up hope and ceases to try. Complications ensue. Pain and suffering increase along with expenses. The relief of death is often long delayed. A full array of prompt rehabilitative services—physical medicine and therapy, occupational and speech therapy, rehabilitation nursing, vocational rehabilitation, psychological assistance—might have prevented this sorrowful outcome.

And what of the victim's family? His wife, his parents, his children, his brothers and sisters? What of their great suffering at seeing their loved one endure this hell on earth?

What if this pitiful creature were your father . . . or you?

Such a tragedy. Such a waste. All that money, and it isn't buying a good life for the recipient. Surely this money can be spent to greater advantage.

What if the victim is fortunate enough to hook into a good rehabilitation program following his stroke? What, then, would life be like in the years after his stroke?

Let's follow the course of events set in motion when one of these more fortunate stroke victims is admitted to a good comprehensive rehabilitation hospital shortly after his attack.

The medical aspects of his stroke are immediately attended to and stabilization of medical problems is achieved as quickly as possible. A block of wood is inserted at the foot of the patient's hospital bed, between his feet and the footboard, to prevent foot-drop—a condition that can develop within hours and impede or even prevent return to a normal walking gait.

Proper nutrition and medication is prescribed and vigorously applied. The highest standards of cleanliness are adhered to. Emotional reassurance is constantly offered to combat depression and aid the patient in achieving a comeback. All personnel are careful to remember that the patient can probably hear and understand everything they say in his presence.

Physical and occupational therapy is started as soon as medically possible to prevent muscle atrophy and invalidism. Speech therapy is begun quickly to prevent permanent speech loss. Supportive family visits are encouraged. Both patient and close relatives are given helpful counseling on how to deal with the stroke and its aftermath. Liberal doses of hope and positive thinking and talking accompany all these. Psychological, neurological and other help is brought in when needed.

The result? Usually the stroke patient will be helped to a degree sufficient to permit return to his home environment—a savings of $13,250 per year or $92,750 during the course of his expected post-stroke lifetime. He will have at least some use of his arms and legs. He will be able to communicate with others. He will be able to take care of most of his own needs around the house—to feed himself, dress himself, wash up and soon return to full-time work or his previous activities, functioning as well as before the stroke.

That's quite a contrast to our pitiful gentlemen in the nursing home.

How much does it cost to buy this kind of post-stroke life for the victim? Costs vary. The programs we will talk most about here cost $8,000 to $11,500. These are one-time expenditures.

Returning to our earlier figures, recall that it costs society an average of $91,750 more to care for a typical unrehabilitated stroke patient over the course of his post-stroke lifetime than it would to care for a rehabilitated one. Subtract this $8,000-11,500 from the $92,750 average and you find a savings of $81,250 to $84,750.

Can it be that it costs *less* to provide the stroke victim a useful, happy life at home than to maintain him in the twilight world of a nursing facility, that it actually *saves money* by performing humanitarian goals?

This is exactly what experience shows us.

THE FACTS IN DETAIL

This section describes the problem of long-term care in America and stroke's contribution to that problem. Statistics regarding the costs of stroke, evidence regarding the effectiveness, costs and cost-benefits of rehabilitation are presented primarily in monetary terms but without losing sight of the broader human benefits of rehabilitation.

The Escalating Problem of Long-Term Care

The umber of older persons is increasing in the United States and the number of elderly and disabled persons is increasing even more rapidly. The number of Americans over 65 years of age, which in 1970 was 20.1 million, reached 23.5 million in 1977. By the year 2000, it is projected that 31.8 million Americans will be over the age of 65. Elderly persons are disproportionately at risk for many illnesses: While only 700,000 elderly disabled persons were in nursing homes in 1970, by 1976 the number increased to 1.6 million. The Congressional Budget Office estimates that 1.8 million older Americans were be in nursing homes in 1980 and that this figure will 2.6 million in 1985.

Costs of long-term care in nursing facilities during the 1970's have been increasing more rapidly than the general inflation rate—even more than for other health and medical services. HEW's *Health, U.S., 1979* reports an increase in such long-term care costs from $1.3 billion in 1965 to $15.8 billion in 1978—over an 1100% increase. Assuming a conservative 5.8 to 6.0% inflation rate, total national expenditures for skilled nursing and intermediate care facilities are projected to reach $20.4 billion by the end of 1980, including both private and public costs. By 1985, that figure will be at least $42.5 billion.

The taxpayer is footing the bill for this traditional care to an ever larger extent. Many federal programs—the Veterans Administration, Medicare, the Older American Act—contribute. But the largest source of government financing, by far, is Medicaid. Medicaid is part of the Social Security Act; its funding is shared by both federal and state governments. It is the major U.S. program for ensuring a minimal level of care for the medically indigent and needy. *Health, U.S., 1979* reports Medicaid spending for nursing homes alone totaled $6.4 billion for fiscal 1977 on the federal level—with equal local or state matching. The CBO-estimated total government expense for institutional long-term care: $10.3 billion for 1980.

Despite great public expenditures, an even greater share of long-term care costs come from family and private sources: more than $12.2 billion for 1980 and only $800 million of this from insurance (again according to CBO). Furthermore, enormous numbers of disabled and elderly persons—in fact, the majority—are cared for by their family and friends at home. The level of expenditures for such care are undoubtedly enormous—though not yet documented.

Stroke is a larger part of the escalating problem of long-term care. National surveys have found that between 11 and 25 percent of patients in nursing homes had had strokes. Still, the problem of stroke is often overlooked—as if nothing could be done about it.

The Problem of Stroke

Stroke—also known as cerebrovascular accident or CVA—covers a varied and complex set of damages that can occur to the brain via the circulatory system. Brain cells are extremely sensitive and must have a continuous flow of oxygen to function properly. A lapse as brief as four minutes can result in death of the affected brain cells—resulting in serious brain damage. The flow of blood and its life-sustaining oxygen can be interrupted by a clot forming in a blood vessel and depriving a part of the brain of its blood supply. Or an embolism may occur as a clot travels through a vessel, lodging in the brain. Or a vessel may burst, causing the blood to spill out into the brain. Death or permanent or temporary paralysis of the body, incontinence (inability to control bladder and anal excretions), and speech problems may follow. Substantial recovery often occurs after the stroke—if the person survives and if he is properly treated and rehabilitated.

Stroke causes more deaths than accidents of all types or any infectious diseases. The National Center for Health Statistics (HEW, *Monthly Vital Statistics Report, Annual Summary for the U.S.*, 1977) estimates that stroke caused 182,840 American deaths in 1977. Stroke affects both sexes and all races, non-whites slightly more than whites. Although no one is exempt, the older a person the greater the risk of stroke. Through research, education and improved treatment, deaths from stroke have been generally decreasing over the years but some physicians have noticed an increase in the incidence of strokes among younger people, e.g., men in their 30's or younger. Stroke is a major threat to our lives—a much larger threat than many people realize.

Stroke is also a major cause of hospitalization. NCHS reports that in 1977 alone, 639,000 patients were discharged from short-stay hospitals with a diagnosis of stroke after an average stay of 13 days. 71% were over age 65.

How frequently do strokes occur? Published estimates of the annual number of strokes in the United States range from just under 400,000 to over 500,000. The recently-completed Nationwide Study of Stroke found 414,000 cases annually in the United States. Because Alaska, Hawaii and—more importantly—cases which do not reach a hospital's records were excluded, the actual number of strokes is even greater. Many victims of stroke die before reaching a hospital.

Others have mild strokes, from which they recover before their physician can induce them to go to a hospital. In addition, many persons have transient ischemic attacks (TIAs). In this mild form, the person may be unaware he is undergoing a stroke. The person may be aware only that he feels bad, is confused, perhaps cannot move or speak as usual and perhaps stays in bed for a week. It has been estimated that TIAs constitute 50% of all strokes. If TIAs and other more severe strokes which never reach a hospital's records could be reliably counted, the actual number of strokes in the United Staes each year could well be found to exceed 1,000,000.

How many people are left alive after having had a stroke? Subtracting 183,000 deaths from the 414,000 stroke victims each year yields 231,000 survivors. The National Health Interview Survey of 1972 found more than 1.5 million living stroke victims, translating to a prevalence of about 7/1,000 in the noninstitutional population. Added to the 1.5 million in the general population would be at least another 122,000 persons in nursing homes, for a total in 1972 of 1,656,000 stroke patients. Similarly, the Nationwide Study of Stroke estimates there were 1.8 million Americans in 1976 with a history of having been hospitalized for stroke.

Due to medical research, the incidence of stroke is on the decline. At the same time, the older population is increasing at a rate of some four million per decade. It is not yet known whether the decline in stroke incidence will be more rapid than the increase in the older population. All that is certain is that stroke is and will remain a major cause of death and disability for Americans.

How long do people live after a stroke? Contrary to popular opinion, the life expectancy of stroke victims is measured in years—not days. Studies show that those stroke patients not dying within a brief period following the attack survive an average of five to seven years; 30% survive more than 11 years. Somewhat less than 50% of stroke victims do die shortly after the stroke, leaving the 231,000 stroke victims each year to be added to the roster of stroke patients currently living in the U.S. Thus, the cost of long-term care and living arrangements becomes a major cost factor.

How disabled are the stroke victims who survive? The 1977 National Health Survey found that 793,000 persons in the non-institutionalized population of the U.S. with stroke were so disabled that their activity was limited. The survey further found that most of those disabled by stroke and living in the community are younger than 65.

Two-thirds of stroke victims at home were found to be unable to carry on their major life activity (e.g., a wage-earner unable to work, a housewife unable to keep house). This is a very high figure when compared with other chronic illnesses. The NCHS found, in fact, that stroke is associated with limitation of activity more frequently than any other chronic circulatory condition—including heart conditions.

Regarding stroke patients confined to nursing homes, the National Nursing Home Survey found that of the 205,000 residents suffering from the effects of a stroke, fewer than 22% were able to move about freely. More than half of the 205,000 patients were confined or restricted to bed. The rest were either confined to the premises or needed a wheelchair to get about.

Of all major disease categories listed by the National Center for Health Statistics in the *Vital and Health Statistics* series, stroke appears to be the most limiting. The severity of many strokes in the population is also shown by the fact that stroke victims tend to reside in somewhat more intensive and expensive institutions than do victims of other diseases.

The Cost of Stroke

Mill and Thompon (1978), of the Harvard School of Public Health, estimated the total direct cost of stroke for 1975 at $4.6 billion. Direct costs include hospital expenses, physician fees, nursing home charges and the like. Total indirect costs for that year were put at $6.6 billion. Indirect costs include earnings lost because of stroke-induced disability or death and did not cover home care expenses by the family or lost wages by family members who had to leave work to care for an invalid. Thus, the total cost of stroke for 1975 would be at least $11.2 billion. More conservatively, the HHS (Nationwide Study of Stroke) estimated that stroke cost the United States $6.627 to $8.543 billion in 1976 alone.

How much does it cost to maintain a stroke patient in a nursing home? The cost of nursing home care varies according to the intensity of nursing care needed. Stroke patients on Medicare cost the government and family together $48-51 daily in nursing home charges in 1976, according to the Heal Care Financing Administration of HHS. This is too high a figure for long-term care for that year, since Medicare pays only for care shortly after leaving an acute care hospital. On the other hand, many patients stayed in personal care and nursing homes for $20-30 per day back in 1976. But stroke patients are more disabled than most other patients.

So what figure is most appropriate for stroke patients? The most recent National Nursing Home Survey reports that the average monthly charge for stroke patients in skilled nursing care under Medicaid was $886 per month ($29.19 per day) for 1977. Inflating this charge to 1980 levels yields an expense of $39.81 per day ($1212 per month; $14,500 per year).

This figure is conservative, for private pay must by law equal or exceed the Medicaid rate. It might be added that there are important variations in the costs of nursing home care between different regions of the country.

If we are to compare the cost of maintaining a stroke patient in a nursing home to the cost of living at home—which we will do later—adjustments must be made to account for costs we have not considered.

The $39.81 per day figure does not include medical expenses such as charges for doctors, special therapy or rehospitalization—a major expense. Also, 61% of stroke patients have spouses and many will continue to bear the cost of their home in hopes that they can somehow return to it. Very small additions might also be made for remaining expenses and consumption beyond the nursing home's daily charge. These expenses are difficult to estimate exactly, but serviceable estimates can be made on the basis of government surveys. Taking these extra but essential expenses into consideration, we arrive at an average 1980 expense of $47 per day to maintain a stroke patient in a facility. This is over $17,000 per year.

Savings Due to Rehabilitation

How much is saved for each stroke patient who is rehabilitated to live at home rather than in a nursing facility? To get this figure, we must subtract the costs of home living that would be saved if a patient went to a nursing home.

What is the cost of home living? Surely it is much less than the cost of institutional care. Since the expense is private, however, a precise estimate is difficult to obtain. Still a serviceable one can be gotten by using the Bureau of Labor Statistics' Annual Budget for a Retired Couple at a lower level of income. (The lower level is surely appropriate, for stroke victims are highly impoverished. Studies report that 51% of prior income is lost after a stroke.) In addition, rehabilitated stroke patients at home sometimes need equipment like a quad cane, shower or eating equipment or home modifications like a short ramp that they wouldn't need or that would be provided if they were in a nursing home. Altogether it should cost about $10.74 daily, or $3920 annually (1980) for a rehabilitated stroke patient to live at home.

Subtracting the expense of home living from that of nursing home maintenance, we find a net savings for each stroke patient rehabilitated to live at home of $36.27 per day, $1104 per month or $13,248 per year.

Actual savings for some stroke patients can be greater. Altogether, it is clear that a great deal of money can be saved if a stroke patient can be rehabilitated to live at home rather than in a nursing facility.

Because the average stroke patient who survives the initial phases of his attack can be expected to live at least seven more years, the loss of each patient who could and should have been rehabilitated, but was not, is $92,736 (7 × $13,248) in 1980 prices. In other words, the empirical, research-based estimate of the average cost due to mistakenly denying rehabilitation to a single stroke patient is $92,736. For patients who survive 11 years—and 30% do—the cost is about $145,700.

Some knowledgeable readers—particularly economists or financial experts—would demand that the above figure be "discounted to present value." What this involves is counting future dollars as less than present dollars, because future events are always less certain than current ones and these monies could be invested to draw interest if it were not spent on rehabilitation. In other words, if additional expenses of nursing home living were covered by insurance, the company's actuary would not have to put aside $92,736 (or $13,248 for each of the seven expected years of life). He would put less money away in some secure investment. Interest would accrue, and the insurance company would still have the money needed to cover the outlay.

How much would an insurance company have to put away to cover an expected outlay of $92,736 spread evenly over seven years? Let's assume the insurance company can earn 10% interest each year on its investments. (This assumption has the advantage of simplicity. Also, a 10% "discount rate" has for years been sanctioned by the Office of Management and Budget for public sector benefit-cost analyses such as the one we're doing here.) Let's also assume that the economy continues to inflate as it did during most of the 1970's. The Consumer Price Index inflated 5.8% per year between 1970 and 1978. So let's use this as an estimate of future inflation. Surely, 5.8% is a very conservative figure in light of recent double-digit inflation.

Going through the calculation, the actuary would find that $82,770 would have to be set aside now to cover the loss for each stroke patient. In other words, every stroke patient our medical care system now neglects to rehabilitate and who winds up in a nursing facility costs our economy an amount equal to $82,770 in 1980 dollars.

However, not every patient can be guaranteed to respond to rehabitation so well that he can live independently at home. How many stroke patients are able to return home after rehabilitation? High quality comprehensive rehabilitation centers typically return 70–80% of stroke patients to home living. These figures have been found to change only very slightly among living stroke patients in follow-up studies some 2 to 12 years after rehabilitation.

Can we say, then, that rehabilitation is 70 to 80% effective with stroke victims? Yes. But to be realistic, we must remember that the outcome of stroke is influenced by many factors besides rehabilitation—factors such as the degree of brain damage inflicted, family and community support, natural healing and complicating medical conditions. What we need is information on how much *more* stroke patients improve after rehabilitation than similar patients who have not received rehabilitation. In scientific terms, we need a "control" group for comparison. Several studies of stroke rehabilitation have done this and found rehabilitation to be highly effective.

One study in the State of Washington took stroke victims at an average of 9.9 months after their initial stroke and gave them comprehensive rehabilitation. Nine months is well after the natural healing which generally occurs after a stroke has run its course. Hence, these patients constitute a control group.

Fifty-six percent (41 of 71) of previously institutionalized stroke patients returned to home living. Taking into account the cost of nursing home living, rehabilitation and so on, this study found that rehabilitation recouped its costs in an average of 21.5 months—much less than the life expectancy of stroke patients. Given the disadvantage of the unusually long period between stroke onset and admission to rehabilitation, during which self-defeating habits can become ingrained, these success rates and financial benefits are impressive.

A more recent study in Minnesota compared outcome of rehabilitated stroke patients to others who , unfortunately, had received only acute medical care at a county general hospital. Sixty-nine percent of the living unrehabilitated group were found in nursing homes in a follow-up eight months to 13 years later, while only 18 percent of the rehabilitated group were similarly institutionalized. Despite imperfect matching between the rehabilitated and non-rehabilitated group, it is again clear that rehabilitation is associated with improved outcomes for the stroke victim.

Other studies have also shown that rehabilitation is associated with improved outcomes. An outstanding one was coducted in the early 1970's in Southern California. It showed that with basic medical care alone, 54.1% of stroke patients were discharged. After comprehensive rehabilitation was instituted, 71.9% of stroke patients were discharged—a 17.8% improvement over the control group. And this gain can only be due to rehabilitation, for the rehabilitated patients did not have milder strokes to begin with. [Actually, the rehabilitated stroke patients had worse functional status at admission to rehabilitation than the comparison group did. In other words, rehabilitation allowed patients to catch up from behind compared to unrehabilitated patients. The 17.8% figure is doubly conservative, for it represents the effectiveness of a program when it was very new in the early 1970's. Programs often do better when they have some time to get well-organized and experienced. Also, stroke rehabilitation programs have improved substantially in the 1970's as new techniques has been devised, treatment gaps have been plugged and experience have been gained. Finally, it might be emphasized that no indication was found that the effect of rehabilitation declines over time. In fact, 23.4% more of the rehabilitation group was found at home at a one-year follow-up than the comparison group.] So a 17.8% effectiveness figure is conservative and solidly based.

How much can we expect to save, then, for each additional stroke victim who is given the advantage of a comprehensive rehabilitation program such as the one in the study above? On average, we can expect to save $14,732 (.178 times $82,765) in discounted 1979 dollars. (Savings would be $16,507 ($92,736 × .178) in undiscounted 1980 dollars even assuming inflation in the future.)

To calculate cost benefits or net savings, we must subtract the cost of rehabilitation from the above figures. What is the cost of high-quality, comprehensive medical rehabilitation? Costs vary between regions of the country and depend on the severity of patients admitted to the particular institution and other factors. Consequently, various figures could be given in the $8,000 to $11,500 range. The cost figure that should be in mind and used in cost benefit calculation, however, is that for the program whose effectiveness was documented above. This cost is $8,328 in 1980 terms. (Note that this $8,328 is the cost of comprehensive rehabilitation over and above the cost of basic acute care. It includes not only inpatient rehabilitation charges, but also physician fees and almost $700 for continuing outpatient rehabilitation, since quality rehabilitation does not cease abruptly at discharge. Cost benefit calculations could be made on programs with higher cost—or lower ones. But then higher—or lower—effectiveness figures would have to be used. So the $8,328 is a fair one.)

The cost benefits of rehabilitating a stroke patient are then crystal clear: For a $8328 investment, one reaps a present-valued $14,732 return. The net savings of making rehabilitation available to a stroke victim not succumbing to the initial attack would then be $6,404 ($14,732—$8,328). [Technically this is a benefit-cost ratio of 1.769 or a 20.7% "internal rate of return" on the investment greater than inflation.] Rehabilitation, then, does not cost money when long-term costs are considered. Rather rehabilitation saves an average of $6,404 for each surviving stroke patient fortunate enough to receive it. Or for every 100 patients admitted to comprehensive rehabilitation rather than being abruptly discharged from acute medical care, net savings would be $640,400 in present-valued dollars.

Considering the national picture, if only half of the 231,000 known persons who survive stroke each year in the United States were to receive comprehensive rehabilitation, total national savings would be $740 million. If 80% could receive rehabilitation, savings would be $1.18 billion in 1980 dollars. Recall that these figures involve discounting future savings. [If future savings were to be counted the same as present ones, savings would be $945 million for half of all stroke survivors, or $1.51 billion for 80%.

Actual dollars saved are likely to be greater since inflation will surely drive up future nursing home and other prices.] Given the fact that inflation is likely to be higher, or using estimates of the effectiveness of rehabilitation that are less conservative, even higher figures for savings can be supported. But however you look at the figures, the point should be clear: stroke rehabilitation is already saving a good deal of money—and has the potential to save a great deal more.

Numerous research studies besides those above could be cited to attest to the benefits of rehabilitation, in either financial or human terms. It might also be added that comprehensive rehabilitation can save money in ways not considered above.

First, some stroke victims can be rehabilitated to return to work. According to HHS's recently completed Nationwide Study of Stroke, the indirect costs of stroke in terms of lost earnings to survivors amounted to at least $438 million in 1976.

Second, rehabilitation decreases the average cost of care regardless of where the patient is discharged. Cost savings are reported even for patients who are sent to institutional living. Researchers have found that functional independence and mobility are highly correlated with costs in extended care facilities. Improvement of a patient from total dependence to partial dependence has been found to reduce care cost by 65%. A further improvement to partial independence saved almost 40% more. Another study in the early 1970's found nursing care homes cost about $8300 per year for completely dependent patients in the northern Midwest. If the patient's dependence became only partial, the cost declined to $6000 per year—and to $2,400 per year if he became independent as a result of rehabilitation services.

In other words, savings will be greatest if the patient is rehabilitated to return home. But any increase in functional independence of the stroke victim due to rehabilitation is going to save money at some level or other. The patient may be able to be cared for in a less intensive and expensive facility like a board and care home instead of a skilled nursing facility. Or the amount of time the patient has to spend recovering in a nursing home may be reduced. In all of these cases, financial benefits will accrue at some level or another in the American economy—to the federal, state or local government, to insurance carriers and payers, or to patients and their families.

Third, rehabilitation also has a favorable effect on earnings of other family members. If the capacity for self-care of disabled stroke victims is increased, family members may be able to remain in their jobs or take new ones, rather than being tied down at home to take care of an invalid. Too often a spouse is faced with the quandary of either quitting work or seeing all earnings eaten up by attendant or institutional expenses. This difficult situation is associated with confusion, fright and lack of preparation, which lead to unwarranted pessimism, despair, bad decisions, physical degeneration and unnecessary institutionalization. Rehabilitation greatly ameliorates this unfortunate situation, saving institutional costs and costs of work loss by family members.

Summary

The major goals of comprehensive rehabilitation for stroke patients are: to relieve suffering; to increase independence in such functional activities as mobility, continence, eating, dressing and other activities of daily living; and to combat self-defeating pessimism and increase the self-esteem and adjustment of the person. Such rehabilitation has been amply shown to represent a wise investment in dollars, easily paying for itself within two years—and saving many thousands of additional dollars for every year thereafter that the patient lives.

In focusing on the economic costs of not rehabilitating stroke patients, however, we have barely touched on the emotional costs. And staggering as the financial costs of not rehabilitating stroke patients may be, these emotional costs are far greater.

Dr. Frederick A. Whitehouse, founder of the American Heart Association's national rehabilitation program and one of the world's leading pioneers in rehabilitation, put it this way in the November-December 1963 *Journal of Rehabilitation* "Stroke Spectrum":

> Not to function is to die; not to exercise faculties causes deterioration; not to be physically active brings atrophy; not to be mentally active leads to breakdown and fantasy; not to have purpose generates despair; not to be in emotional contact with others and the external world encourages retreat; not to be useful leads to self-abasement and unhappiness.
>
> In other words, living purposefully and usefully may be the difference between the home and a mental institution, between relative independence and custodial care, between dignity and pity, between participation in life and withdrawal and death. At stake is a test not only of our rehabilitation philosophy, but of society's reverence for human life.

This emotional cost is not limited to the stroke victim alone; his family and close friends share his grief and despair when help is not given.

Writing in the same "Stroke Spectrum," President John F. Kennedy stated:

> Having seen personally what a stroke can do to a person, having seen what a vital difference proper treatment and care can make. . . . I sincerely hope each and every person who reads this message will . . . take to heart the advice . . . to start treatment and all necessary therapies early, to treat the stroke patient as an adult human being with all the dignity and respect this entails, and to try to the fullest of his ability to help ensure the happiest, most productive and meaningful post-stroke life possible for those who have been unfortunate enough to suffer this form of accident.

POLICY IMPLICATIONS

Recognition of the value of stroke rehabilitation has been slow in coming to the national consciousness. The principal hesitancies among physicians, Congress, regulators, insurance companies and other involved publics regarding full endorsement of rehabilitation has been the question of worth of service in relation to human outcome and cost benefit for the national good.

In the past, the greatest power encouraging the above publics endorsing rehabilitation has been the satisfied consumer—the patient and his family—receiving the product of rehabilitation.

It is hoped that even the most critical financial actuary or result-oriented resource allocator will recognize the value of stroke rehabilitation from a cost-benefit, outcome-focused and humanitarian point of view after digesting the data presented in the previous section, and that he will now join the consumer in full endorsement of the value of comprehensive stroke rehabilitation in this country.

Congress has permitted acute medical stroke rehabilitation to be funded via the Medicare and Medicaid programs. Thus, whether by planning or by chance, Congress permitted one of the most cost-effective and beneficial programs to emerge.

However, there remains a reluctance on the part of Congress to fully endorse rehabilitation, possibly stemming from lack of public data on the excellent return on investment that can be achieved from comprehensive rehabilitation, or perhaps from lack of a powerful advocacy group pressing daily for more money. Whatever the reason, the data are available for review—and the time is now for the allocators of health care dollars to recognize the magnitude of the stroke problem and the fact that rehabilitation can assist greatly in solving that problem.

Current discontinued savings could reflect an annual savings to society of $740 million to $1.8 billion in 1980 dollars. In view of these facts and the fact that stroke will continue to be a giant health problem, allocators of health resources should be encouraged to consider making increased rehabilitation a top priority of the health care delivery system.

Stroke rehabilitation is not just another "expensive" way of lessening the suffering of sick persons, although it does do that. It also actually *saves* money by allowing stroke victims and their families to care for themselves, rather than—in fright and confusion—to rely on nursing homes. Stroke rehabilitation achieves a respectable rate of return 20.7% greater than inflation by conservative methods of analysis. If such a return could be obtained in an open market investment, a multitude of investors would demand a chance for the opportunity.

Although there are no exact figures, only a fraction of all stroke victims are currently being sent to rehabilitation. One study, for instance, found that less than 2% of hospitalized stroke patients in a Los Angles Professional Standards Review Organization, excluding intra-hospital transfers, went to rehabilitation. There are entire states in our country without a comprehensive medical rehabilitation hospital. Neglect of such magnitude not only lessens the quality of life for disabled persons, but actually increases total costs—to the tune of hundreds of millions of dollars wasted annually.

It was not the intent of this paper to cover the entire spectrum of rehabilitation, but only stroke rehabilitation. Future papers will present cost-benefit and outcome evidence for spinal cord injury, brain injury and vocational rehabilitation, as continuing evidence that rehabilitation in general deserves highest priority in the health care spectrum. The sooner allocators expend the necessary dollars for rehabilitation, the sooner productivity will be improved and costly welfare maintenance costs will be reduced.

A review of the past decade of Congressional action regarding increased research and demonstration monies in rehabilitation (Rehabilitation Services Administration allocations) indicates insufficient knowledge regarding the rich investment opportunity that rehabilitation provides. During this rather flat investment or allocation period by Congress, there has been a profound increase in use of rehabilitation services by the private and public sectors. The critical need now is for Congress to allocate dollars for practical and applied research in discovering alternative methods for more cost-*effective* delivery of rehabilitation services in all major spectra of disability.

Most research that has been sponsored by the Rehabilitation Services Adminstration in the past was channeled to universities. The premise upon which this distribution occurred may rest with the assumption that universities are where bright people congregate and thus richer ideas may emerge to improve the delivery system. Perhaps that assumption is valid, but it is also true that universities can afford full-time advocates to muscle dollars for research. The latter fact has been more clearly observed by the authors than has the former assumption. By contrast, providers of comprehensive rehabilitation services have been struggling to improve service day by day with equally bright personnel within a competitive marketplace and a consumer-responsive service system. Often without any government support at all, out of their own weekends, evenings and pockets, they attempt to do research to document or determine the effectivenesses of their innovations in treatment.

It is the authors' bias and their intent that comprehensive rehabilitation service centers be considered for grant dollars to develop more cost-effective methods for rehabilitation service delivery, that applied research dollars be allocated to study community service needs and that resources be provided to implement same.

Evidence to support the principle that the private nonprofit sector is capable of such developmental work is overwhelming throughout the nation. An institution with which the authors are familiar has shown an enlightened and assertive capability to speak to the needs of consumers over a 40-year period. This institution, one of many throughout the country, relates to 1,200 physicians in a 100-mile geographic area serving a population of seven million persons. It has 66 acute rehabilitation beds, and has provided services principally to stroke victims. Over the last seven years, it broadened the service disability base to include most major disabling conditions, including spinal cord injury, brain injury and chronic back pain.

During this period of time, it formulated and made operational a chronic back pain treatment program for industrially injured workers. This program has been able to consistently return 71% of patients to employment—patients who had been disabled an average of 3.6 years prior to the program. Furthermore, cost of treatment is substantially less with comprehensive rehabilitation than with traditional treatment: $25,218 as opposed to $42,439—a $17,221 savings. Clearly, sophisticated, systematic rehabilitation is markedly more cost-effective than traditional, surgery-centered and uncoordinated treatment.

This rehabilitation institution also formulated and made operational an Adult Day Health Care Program which serves discharged stroke patients who are so disabled as to not be capable of caring for themselves at home and therefore, would likely require institutionalization in a skilled nursing care facility. In addition to the patient and family being more satisfied with the Adult Day Progam over a skilled nursing facility, the cost savings per person served in the Day Program over a skilled nursing facility is $25 per day. Over a three-year period of operation, the Day Program has achieved a total savings of $481,808 from but 20 persons. If only 10% of the 122,000 stroke patients in nursing homes today could be diverted from that intensive and oppressive level of care, the total savings would approximate $98 million annually.

This same institution formulated and made operational a brain injury rehabilitation program wherein comatose and pre-comatose patients formerly sent to skilled nursing facilities for life, were rehabilitated to semi-independent function in the community. This program, only 18 months old, will require additional time to collect meaningful data, but preliminary evidence shows similar returns when compared with other rehabilitation programs.

These examples are but four of the 30 innovative efforts developed in this institution. The effort by this one institution is reflected in varying degree in some 2,000 other rehabilitation facilities throughout the United States.

It is interesting to note that the administrators of the Medicaid and Medicare programs did not encourage such innovation but in fact resisted compensating for such services on the basis that the techniques were not proven—after six years of empirically validated evidence of worth.

This illustrates the lack of overall planning in rehabilitation efforts and a piecemeal approach to life planning for the severely disabled. The waste of dollars and bureaucratic energy could be measurably reduced with an appropriate rehabilitation plan design in both private and public sectors.

Finally, cost-effective treatment innovations are more—or at least equally—likely to be developed at such smaller, service-oriented hospitals than at large, research-and-teaching university hospitals. University hospitals are necessarily unusually expensive and atypically elaborate in their organization of service delivery. Though this is fine for purposes like teaching, it is no advantage when it comes to cost-effective treatment innovations. Less elaborate, smaller, service-oriented institutions should be somewhat more likely to yield research and innovations that are cost-effective.

The point here is that significant research and demonstration resources should be directed to these private, nonprofit rehabilitation facilities to impact major chronic health problems like stroke in a cost-effective way. For without such resources to develop cost-effective alternatives in rehabilitation, the quality of life of disabled persons will remain unnecessarily poor and health care costs will continue to escalate beyond their reasonable capacity to pay.

A SINGLE RECOMMENDATION

The cost benefits that have been shown to accrue from comprehensive rehabilitation for stroke patients can be attained in additional areas of disability as well. What is needed—*and it is needed now*—is the development of new alternatives to properly rehabilitate all those in need of rehabilitation services in the most cost-effective way.

It is therefore recommended that Congress ask the Rehabilitation Services Administration, in cooperation with the National Association of Rehabilitation Facilities and the private insurance industry, to develop a national rehabilitation plan to deal with our future and to include the private sector rehabilitation facilities in that plan. Resources to develop such a plan should be authorized in the 1980-1981 Congress.

The sooner such a plan is initiated, the sooner our country can start:

- offering comprehensive rehabilitation services to all stroke patients and others in need of such services, thus easing the costly and unnecessary suffering of so many millions of Americans; and
- saving the hundreds of millions of dollars annually that we are now wasting by mistakenly denying rehabilitation to those who could benefit from its healing powers.

REFERENCES

Anderson, E., Anderson T.P. and Kottke, F.J. Stroke rehabilitation: maintenance of achieved gains. *Archives of physical medicine and rehabilitation, 58,* August 1977, 345-352.

Anderson, T.P. Stroke rehabilitation: assessing outcome. *Archives of physical medicine and rehabilitation, 59,* 1978, 170-174.

Anderson, T.P., Baldridge, M. and Ettinger, M.G. Quality of care for completed stroke without rehabilitation: evaluation by assessing patient outcomes. *Archives of physical medicine and rehabilitation, 60,* March 1979, 103-107.

Anderson, T.P., Bourestom, N., Greenberg, et al. Predictive factors in stroke rehabilitation. *Archives of physical medicine and rehabilitation, 55,* 1974, 545-553.

Anderson, T.P. and Kottke, F.J. Stroke rehabilitation: a reconsideration of some common attitudes. *Archives of physical medicine and rehabilitation, 59,* April 1978, 175-181.

Bryant, N.H., et al. Comparison of care and cost outcomes for stroke patients with and without home care. *Stroke, 5,* January-February 1974.

Bureau of the Census (U.S. Department of Commerce). *Statistical Abstract of the United States, 1979.* Washington, D.C.: Government Printing Office, 1980. (See also 1978 *Abstract.*)

Bureau of the Census (U.S. Department of Labor, J. Siegel, et al. personal authors) Demographic aspects of aging and the older population in the U.S. *Current population reports, special studies,* series P-23, no. 59 Issued 1976, revised 1978.

Bureau of Labor Statistics (U.S. Department of Labor) Summary of Annual Budgets for a retired couple at three levels of living, Urban U.S. Autum 1974 (USDL 75-427). Washington, D.C., 1975.

Bureau of Labor Statistics (U.S. Department of Labor) "News" Washington, D.C., April 29, 1979.

Cartlidge, N.E.F., Whisnant, J.P. and Elveback, L.R. Carotid and vertebral-basilar transient cerebral ischemic attacks: a community study. Rochester, Minnesota. *Mayo Clinic Proceedings, 52,* 1977, 117-120.

Casa Colina Hospital for Rehabilitative Medicine. Management of back injuries. Guidelines for planning. Sponsored by The Zenith Insurance Company. Beverly Hills, California, June 3, 1979.

Congressional Budget Office (U.S. Congress). *Long-term care for the elderly and disabled.* Budget issue paper. Febraury 1977.

Congressional Budget Office (U.S. Congress). *Long-term care: actuarial cost estimates.* CBO technical analysis paper. August 1977.

Conneally, P.M., Dyken, M.L., Futty, D.E., et al. Cooperative study of hospital frequency and character of transient ischemic attacks. VIII. Risk factors. *JAMA, 240,* August 25, 1978, 742-6.

Emlet, H.E. Jr., Williamson, J.W., et al. *Estimated health benefits and costs of post-onset care for stroke (in a three state area: Minnesota, North Dakota).* Analytic Services, Inc., Arlington, Virginia, September 1973.

Feigenson, J.S. Stroke rehabilitation: effectiveness, benefits, and cost. Some practical conclusions. *Stroke, 10,* January-February 1979, 1-4.

Feigenson, J.S., Feigenson, W.D., Gitlow, H.S., McCarthy, M.L. and Greenberg, S. Outcome and cost for stroke patients in academic and community hospitals. Comparison of two groups referred to a regional rehabilitation center. *JAMA, 240,* (17), October 20, 1978, 1878-1880.

Feigenson, Joel S., Gitlow, H.S. and Greenberg, S.D. The disability-oriented rehabilitation unit-a major factor influencing stroke outcome. *Stroke, 10,* January-February 1979, 5-8.

Feigenson, J.S., McCarthy, M.L., Greenberg, S.D. and Feigenson, W.D. Factors influencing outcome and length of stay in a stroke rehabilitation unit. Part 2. Comparison of 318 screened and 248 unscreened patients. *Stroke,* November-December 1977, *8*(6), 657-662.

Feigenson, Joel S. M.D., McDowell, Fletcher H. M.D., Meese, Philip, McCarthy, Mary Lou and Greenberg, Susan D. Factors influencing outcome and length of stay in a stroke rehabilitation unit. Part 1. Analysis of 248 unscreened patients—medical and functional prognostic indicators. *Stroke,* November-December, 1977, *8,* 651-656.

Ford, A.B. and Kartz, S. Prognosis after strokes. Part I: Critical review. *Medicine* (Baltimore), *45,* 1966, 223-236.

Garraway, W.M., Whisnant, J.P., et al. The declining incidence of stroke. *New England journal of medicine, 300*(9), March 1979, 449-452.

Granger, C.V. and Greer, D.S. Functional status measurement and medical rehabilitation outcomes. *Archives of physical medicine and rehabilitation, 59,* March 1976, 103-109.

Granger, C.V., Lester, D.S., et al. Stroke rehabilitation: analysis of repeated Barthel Index measures. *Archives of physical medicine and rehabilitation, 60,* January 1979, 14-17.

Granger, C.V., Sherwood, C.C. and Greer, D.S. Functional status measures in a comprehensive stroke care program. *Archives of physical medicine and* rehabilitation, *58,* December 1977, 555-561.

Gottlieb, H., Strite, L.C., Koller, R., et al. Comprehensive rehabilitation of patients having chronic low back pain. *Archives of physical medicine and rehabilitation, 58,* 1977, 101-108.

Haberman, S., Capildeo, R. and Rose, F.C. The changing morality of cerebrovascular disease. *Quarterly journal of medicine, 47,* 1978, 71-88.

Haddon, P.A. An evaluation of a stroke rehabilitation program. Unpublished M.A. Thesis. California State University at Fullerton, May 1977.

Klein, B., Miller, P. and Miller, L.S. PSRO Audit of appropriate discharge placement of stroke patients. *Archives of physical medicine and rehabilitation, 59,* 1978, 552.

Kottke, F.J. Historia obscura hemiplegiae. *Archives of physical medicine and rehabilitation, 55,* 1974, 4-13.

Lehmann, J.F., et al. Stroke rehabilitation: outcome and prediction. *Archives of physical medicine and rehabilitation, 56,* September 1975, 383-389.

Lehmann, J.F., DeLateur, B.J., et al. Stroke: Does rehabilitation affect outcome? *Archives of physical medicine and rehabilitation, 56,* 1975, 375-382.

Levy, R.I. Stroke decline: implications and prospects. *New England Journal of Medicine,* 300(9), March 1, 1979, 490-491.

Mackey, F.G., Haddon, P.A., et al. Stroke rehabilitation: Is it worthwhile? Paper presented at Assembly of American Academy of Physical Medicine and Rehabilitation, San Diego, California, November 1976. Abstract in *Archives of Physical Medicine and Rehabilitation, 57* (November), 1976, 547-548.

Mackey, F.G. Is stroke rehabilitation worthwhile? St. Jude Hospital and Rehabilitation Center, Fullerton, California, 1977.

Matsumoto, N., Whisnant, J.P., et al. Natural history of stroke in Rochester, Minnesota, 1955-1969; extension of previous study. *Stroke, 4,* 1973, 20-29.

Mills, E. and Thompson, M. The economic costs of stroke in Massachusetts. *The New England Journal of Medicine, 299* (August 24), 1978, 415-418.

National Center for Health Statistics (USDHEW, PHS). *Health, United States, 1979.* (PHS 80-1232). Hyattsville, Maryland, 1980. See also 1978 edition.

National Center for Health Statistics (USDHEW, PHS). Prevalence of chronic circulatory conditions, U.S., 1972. *Vital and Health Statistics,* Series 10, No. 94. Rockville, Maryland, September 1974.

National Center for Health Statistics (USDHEW, PHS). Limitations of activity and mobility due to chronic conditions, U.S.—1972. *Vital and Health Statistics,* Series 10, No. 96. Government Printing Office, Washington, D.C., November 1974.

National Center for Health Statistics (USDHEW, PHS. Health Resources Administration, Charles S. Wildner personal author. Limitation of activity due to chronic conditions, U.S. 1974. *Vital and Health Statistics,* Series 10, No. 111. Rockville, Maryland, June 1977.

National Center for Health Statistics (USDHEW, PHS). Chronic conditions and impairments of nursing home residents: U.S.—1969. *Vital and Health Statistics,* Series 12, No. 22. Rockville, Maryland, December 1973.

National Center for Health Statistics (USDHEW, PHS). Profile of chronic illness in nursing homes. U.S. National Nursing Home Survey, August 1973-April 1974. *Vital and Health Statistics*, Series 13, No. 29. Hyattsville, Maryland, December 1977.

National Center for Health Statistics (USDHEW, PHS). Charges for care and sources of payment for residents in nursing homes. U.S. National Nursing Homes Survey, August 1973-April 1974. *Vital and Health Statistics*, Series 13, No. 32. Hyattsville, Maryland, November 1977.

National Center for Health Statistics (USDHEW, PHS, B. Haupt). Utilization of short stay hospitals: annual summary. Hospital discharge summary for 1977. *Vital and Health Statistics*, Series 13, No. 41. Hyattsville, Maryland, March 1979.

National Center for Health Statistics (USDHEW, PHS, J.F. Van Nostrand, et al. personal authors). The National Nursing Home Survey: 1977 summary for the United States. *Vital and Health Statistics*, Series 13, No. 43. Hyattsville, Maryland, July 1979.

National Center for Health Statistics (USDHEW, PHS). Utilization of short stay hospitals, annual summary of the U.S., 1977. *Vital and Health Statistics*, Series 13, No. 41. Bethesda, Maryland, March 1979.

National Center for Health Statistics (USDHEW, PHS). *Vital Statistics of the United States 1975, Vol. II--Mortality. Part A.* (*PHS 79-1114*). Hyattsville, Maryland, 1979.

Rehabilitation—stroke: post-hospital care and follow-up. *Patient care*, 13(2), 30 January 1979, 94-95, 99, 102 passim.

Robins, M., Cahill, J.I., et al. Nationwide Study of Stroke. Final Report. Report prepared for the National Institute of Neurological and Communicative Disorders and Stroke, Bethesda, Maryland, by Westat, Inc., 11600 Nebel St., Rockville, MD 20852, January 1979.

Robins, M., Cahill, J.I., Haines, C.M., Simmons, W.R. and Woolsey, T.D. *Nationwide study of stroke: executive summary.* December 1978. (Available from Westat Research, 11600 Nebel St., Rockville, MD 20852, or National Institute of Neurological Diseases, Communicative Disorders and Stroke.)

Stallones, R.A., Dyken, M.L., Fang, H.C.H., Heyman, A., Seltser, R. and Stamler, J. Epidemiology for stroke facilities planning. *Stroke*, 1972, 3, 360-371.

Verrone, G.A. and Nde, M.F. Financial expenditures for the care of cerebrovascular disease patients in an urban setting. *Public health reports*, 92(3), May-June 1977, 272-9.

Whisnant, J.P., Fitzgibbons, J.P., Kurland, L.T., et al. Natural history of stroke in Rochester, Minnesota, 1945 through 1954. *Stroke*, 2, January-February 1971, 11-22.

NARF Monograph Series

MEDICAL REHABILITATION

WHAT IT IS
AND
WHERE IT IS:

A DISCUSSION

November 1988

NARF
National Association of
Rehabilitation Facilities
P.O. Box 17675
Washington, D.C. 20041
(703) 648-9300

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FOREWORD

This monograph was prepared by the National Association of Rehabilitation Facilities (NARF) in response to increasing interest by payors for rehabilitation and others who want to know more about what rehabilitation is and where it occurs.

Rehabilitation includes both vocational and medical services. It is an essential component of the health care delivery system which stresses the value of each individual. For persons with disabilities and their families, rehabilitation programs and services play a critical role in improving the quality of their life. This monograph focuses primarily on medical rehabilitation including the vocational components. Programs which focus solely on vocational services are not explored in full here. NARF anticipates that a second monograph may be developed at a later date exploring more completely the vocational sector of the industry.

NARF has developed this monograph to assist physicians not specializing in medical rehabilitation, unions, employers, insurance companies, managed care payors, states, the Federal Government, and other purchasers of services. It should be viewed only as a general description of the industry.

NARF congratulates the members of the Task Force who devoted considerable time, attention and expertise to its development. NARF also thanks Ted Hipkens, senior consultant, Rehabilitation Institute of Pittsburgh, and Mae Hightower-VanDamm, Delaware Curative Workshop, for their perspectives on the development of medical rehabilitation in the United States.

The chairman, members of the Task Force and I hope that this paper will be helpful to those seeking to know more about medical rehabilitation.

Edmund S. McLaughlin
President

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EXECUTIVE SUMMARY

In October, 1985, NARF developed its Task Force on the Spectrum of Care in Rehabilitation. One of its tasks was to "continue its examination of the different levels of rehabilitation care and develop descriptors to be used to explain such levels of care to the medical rehabilitation industry consumers."

The Task Force met consistently for over two years to develop this document in an effort to explain medical rehabilitation, what it is and where it is. In the course of its discussion, the Task Force decided that the document should be written primarily for the payors of medical rehabilitation with a separate, shorter document for consumers yet to be developed. The document is intended to be primarily descriptive of the medical rehabilitation field at this time and it is not to be viewed as guidelines or standards.

Chapter II includes a working definition of medical rehabilitation. Medical rehabilitation refers to the evaluation, diagnosis, treatment, and procedures which seek to minimize physical and cognitive impairments, prevent institutionalization and reinstitutionalization, maximize functional ability, and restore lost functional capacity, thereby reducing the impact of a disability on the quality and productivity of the patient's life. The purpose of rehabilitation has been defined in various ways with the primary emphasis being on restoring a person's ability to function in a normal manner. Dr. Frederick J. Kottke states that "comprehensive rehabilitation's [goal] is to restore optimal physical function and psycho-social-vocational restoration to enable the patient to become a productive participant in the community." (Archives of Physical Medicine and Rehabilitation, January, 1980.)

Medical rehabilitation may start during the acute care phase. It seeks to get patients moving, walking, talking, and dressing and eating by themselves and, most importantly, returning patients home to their families, back to work, school and other normal activities. The maximum benefit of rehabilitation services and programs is achieved when the patient is evaluated as early as possible for rehabilitation potential, and rehabilitation intervention is begun promptly.

Chapter II also addresses the historical development of rehabilitation. It covers the development of physical medicine and rehabilitation as the medical specialty known as physiatry. The American Board of Physical Medicine and Rehabilitation certifies physicians in physiatry.

It also covers the historical development of medical rehabilitation facilities. Most of the development of medical rehabilitation hospitals began during World War II and expanded after that.

Rehabilitation units in acute care hospitals have evolved since the 1950s and have grown with the advent of the Medicare and Medicaid programs. The first outpatient rehabilitation facilities date from early in the century and have grown considerably. By 1987 there were over 900 different outpatient rehabilitation facility program providers. Traditionally, nursing facilities have focused primarily on the needs of long-term patients. These facilities have provided some rehabilitation services but not at an intense level, nor have they usually been formally structured or medically directed. However, in this decade there have been a few nursing facilities which have developed medical rehabilitation programs usually focused in the area of head injury. These are relatively new entrants into the rehabilitation field. Medical rehabilitation providers also include home health agencies initially started by visiting nurses associations. Other new entrants include community reentry programs and transitional living programs.

Medical rehabilitation is not complete without addressing its vocational rehabilitation components. The forerunners to today's vocational rehabilitation programs were sheltered workshops established in the 1930s. Vocational rehabilitation programs today address persons with developmental disabilities, mental and physical disabilities, and cognitive disabilities. They have become integral to comprehensive medical rehabilitation.

The third part of Chapter II addresses conditions necessitating rehabilitation. People become rehabilitation patients because of functional impairments resulting from trauma, disease, or congenital deformity. The diagnosis of a patient's condition does not drive the need for rehabilitation; functional impairments do. The most common conditions treated in a medical rehabilitation setting include, but are not limited to, back injury, spinal cord injury, head injury, hip fracture, amputations, strokes, arthritis, neurological disease and trauma, and problems related to cancer, cardiovascular disease, pulmonary disease, chronic pain, and musculoskeletal diseases. As the population ages and as medical technology advances, the number of people coming into rehabilitation programs has been increasing, and this increase is expected to continue.

In general, medical rehabilitation seeks to rehabilitate/habilitate people so they can live in the least restrictive, least costly environment at their highest possible level of independence.

Chapter III discusses the role and function of patient evaluation and placement. The patient characteristics described in Chapter V must all be considered during the evaluation process in order to determine the most appropriate place of care described in Chapter VI. This evaluation process requires expertise in medical rehabilitation to determine prognosis for recovery from illness of trauma and make a judgment as to appropriate placement. Therefore, all patients with functional impairments should enter the rehabilitation system for evaluation and treatment. Presently, patient evaluation and placement cannot be reduced to a formula since the process involves the evaluation of a number of factors, few of which are completely quantifiable. Diagnosis and/or etiology of condition should not be the sole criteria for the selection of a rehabilitation program.

Chapter IV describes the role that the availability of care plays in medical rehabilitation. The ideal community would have high quality programs available at each point on the spectrum of care. Many areas of the country, unfortunately, do not have some or all of such programs available. However, they are attempting to meet the needs of their communities especially when appropriate referrals are made and followed. The availability of each program is critical to local physicians, the rehabilitation team, patients and families, and other consumers in making decisions about what type of care patients should receive, whether they should be sent out of the community to receive such care, and the patient's ultimate, optimal functioning. Another critical factor influencing placement is insurance or other coverage for rehabilitation. Many individuals and families may think they have appropriate coverage when they do not. The balance of the chapter describes some of these determinants and other issues involving the availability of care.

Chapter V discusses the characteristics of persons who can benefit from comprehensive medical rehabilitation programs or rehabilitation services. Frequently, patients who have the potential to improve their functional status are not identified by nonrehabilitation professionals.

Often patients have both medical and nonmedical needs. Medically, they may be in a labile (i.e., fragile) condition. In determining potential for rehabilitation, the person is evaluated by the physiatrist or otherwise qualified physician and members of the interdisciplinary rehabilitation team to determine what programs or services are needed and in what frequency and duration. The evaluation identifies the patient's problems and status in each area. A rehabilitation evaluation includes rehabilitation potential; health status; functional status including mobility, activities of daily living, safety, cognition, behavior, communications, psycho-social status; social status; and vocational and education status. This chapter discusses the characteristics of these persons generally and then groups them into broadly descriptive categories of patients who, because of these characteristics, may benefit from a rehabilitation program. These characteristics are descriptive of a patient's present status but that may change at any time. The balance of this chapter describes approximately eight patient groupings.

Chapter VI describes the differences between comprehensive medical rehabilitation programs and rehabilitation services. The distinguishing characteristic of a rehabilitation program as opposed to a rehabilitation service is that the programs encompass coordinated, interactive, goal-directed integrated services under the direction of a physiatrist or otherwise qualified physician and interdisciiplinary team. It examines the specific characteristics of a rehabilitation program and describes the evolution of disability specific programs being developed as subsets of general comprehensive rehabilitation programs. It also describes the types of rehabilitation programs that exist currently.

Rehabilitation services, on the other hand, are provided by an individual discipline. Each discipline provides its own patient evaluation for that particular service without coordinated treatment goals, process, or information from other disciplines. This chapter also describes where rehabilitation services are found.

The monograph also includes a glossary of terms used, selected references, and questions to consider when looking at medical rehabilitation programs and services.

I. INTRODUCTION

This monograph is published by the National Association of Rehabilitation Facilities to provide an overview of medical rehabilitation. It is intended for the use of agencies and companies providing coverage of medical rehabilitation programs and services through government programs and insurance contracts. The paper describes the rehabilitation process and the various types of rehabilitation programs and services that are generally available.

Medical rehabilitation is a fairly recent addition to the health care services generally available in the United States, having its advent in this century and significant development only since World War II. It is, however, a medical specialty that is in considerable demand and one which will grow in the future.

In 1947 the American Board of Physical Medicine was established. It was retitled the American Board of Physical Medicine and Rehabilitation (PM&R) in 1949. Since the 1940s, medical rehabilitation has grown tremendously, reflecting increased recognition of and the need for such services. Rehabilitation programs and services are present to some degree in each state. Facilities providing such services are concentrated in the East, West and Midwest, with major growth now occurring in the Central West and South. Outpatient rehabilitation services are expanding throughout the nation.

Rehabilitation services will expand to meet the needs of patients in underserved areas, of which there are many, and to meet the increasing demand for rehabilitation resulting from demographic factors and changing lifestyles. Many times nonrehabilitation professionals do not see a patient's rehabilitation potential. This is the phenomena of the invisible rehabilitation patient. The fact that patients with residual disabilities can improve their functional status is more likely to become clear only when they are evaluated by rehabilitation professionals.

A significant portion of patients requiring medical rehabilitation are elderly. In 1987, approximately 12 percent of the U.S. population was over the age of 65. By 2000 this group is projected to account for over 13 percent of the population. People in this age bracket are more susceptible to medical conditions which may result in a disability, particularly strokes, arthritis, and hip fractures.

In addition to the growing need to serve the needs of the elderly population, rehabilitation is also providing services to increasing numbers of younger patients who experience traumatic injuries or have congenital impairments. Medical science has developed the means to save the lives of people injured in motor vehicle collisions, industrial accidents, sports, incidents of violence, and similar causes of trauma. This factor, coupled with an increasing number of such incidents, is expanding the need for services to assist such patients to regain the ability to function effectively in society.

Medical rehabilitation consists of an integrated program of therapies focused on the problems of a particular patient to help that patient regain his or her maximum level of function and/or to compensate for any residual disabilities. Medical rehabilitation is directed by a physician with the participation of such other health professionals as physical therapists, occupational therapists, rehabilitation nurses and others. A rehabilitation program consists of helping the patient help himself through an often rigorous therapeutic program. In contrast to more acute forms of medical care which typically apply medical techniques to a passive patient, rehabilitation works with the participation of the patient and family. Thus, a rehabilitation program requires active patient and family involvement and commitment. It also requires the integration of therapeutic medical techniques with social, psychological and vocational services to facilitate the patient's improvement. It seeks to improve patient's functional abilities so that they can live in the least restrictive environment.

Rehabilitation facilities and programs are, like most medical and social services, undergoing significant changes. This is occurring because of increasing demand and the development of new methods and techniques for their delivery.

As rehabilitation has grown, so have questions about it. Patients, families, purchasers and payors of medical rehabilitation are asking: What is it? Where is it? How does it differ from other medical areas? What does it cost and is it cost beneficial? How do I know if I am covered for it?

This monograph provides:

- an overview of the rehabilitation industry, definitions and historical background (Chapter II)
- a description of patient evaluation and placement (Chapter III)
- a discussion of the impact of the availability of care (Chapter IV)
- a description of the characteristics of persons who need rehabilitation (Chapter V)
- a description of rehabilitation programs and services (Chapter VI)

A discussion of rehabilitation programs would not be complete without at least a brief review of insurance coverage of rehabilitation services.

There are various types of insurance policies that provide coverage for rehabilitating services. These include health and accident, workers' compensation, health maintenance organizations, liability (primarily automobile), case managers and government programs (primarily Medicare and Medicaid). An extensive discussion of each of these is beyond the scope of this paper. However, all readers are encouraged to evaluate the coverage available to them or their families. Workers' compensation and liability coverage have a history of supporting rehabilitation, primarily to reduce dependency and the need for long-term income maintenance. Health and accident policies may provide full coverage for rehabilitation. Some policies with less comprehensive coverage are more restrictive.

In reading this document, the reader needs to keep in mind:

- This monograph attempts to describe the types of programs and services now available, or becoming available, and their relevance to the needs of various types of patients. However, the industry is rapidly changing and growing. NARF expects that new types of providers not addressed here will continue to emerge. It represents a compilation of the national picture and does not account for regional difference in types of and availability or care and this caveat should be kept in mind while reading it.
- At times some patient placement decisions may be reimbursement driven. Some of these decisions are not appropriate medical decisions because, as a result, the patient is not restored to his or her maximum level of function and must be readmitted usually to acute care, incurring unneeded costs. Studies conducted recently by the Health Insurance Association of America and the Insurance Company of North America show rehabilitation to be very cost effective.
- This document should be viewed as a general description of the industry and not as guidelines or standards. Each person's needs at the moment and the availability of care will dictate appropriate referral and services.

II. AN OVERVIEW

A. Rehabilitation: A Working Definition

The American Heritage Dictionary defines rehabilitation as restoring "a handicapped...person to useful life through education and therapy." The goal and purpose of rehabilitation have been defined in various ways with the primary emphasis on restoring a person's ability to function in a normal manner. Dr. Frederic J. Kottke states that "comprehensive rehabilitation's [goal] is to restore optimal physical function and psycho-social-vocational restoration to enable the patient to become a productive participant in the community." (Archives of Physical Medicine and Rehabilitation, Jan., 1980.)

Medical rehabilitation refers to evaluation, diagnosis, treatment and procedures which seek to minimize physical and cognitive impairments, prevent institutionalization and reinstitutionalization, and maximize functional ability, thereby reducing the impact of a disability on the quality and productivity of the patient's life. Some people refer to disabilities as handicaps or refer to persons with disabilities as being handicapped. For the majority of practitioners and advocates, the preferred terms are "persons with disabilities" or "physically or mentally challenged persons." The emphasis is on the individual's ability to function, and not on the disability.

Acute care given in the emergency room or in the general hospital focuses on assuring the patient's survival. Once it is determined the patient will survive, medical rehabilitation focuses on restoring lost functional capacity and eliminating disabilities. Comprehensive rehabilitation promotes maximum levels of physical independence, as well as psychological, social, economic, vocational and personal adjustments in the shortest period of time. Rehabilitation helps people who have congenital deformities and diseases, those with chronic diseases, those suffering the results of a severe accident, and other disorders. Over 80 percent of rehabilitation patients served in rehabilitation hospitals and units go home, according to a study conducted by the National Association of Rehabilitation Facilities.

Medical rehabilitation may start during the acute care phase. It seeks to get patients moving, walking, talking, dressing and eating by themselves and, most importantly, returning patients home to their families and back to work, school, and other normal activities. The maximum benefit from rehabilitation services and programs is achieved when the patient is evaluated as early as possible for rehabilitation potential and rehabilitation intervention is begun promptly.

B. Historical Development of the Medical Rehabilitation Industry

1. Physical Medicine and Rehabilitation as a Medical Specialty

The concept of comprehensive care to obtain a patient's optimal function in his or her environment was advanced because of the many injuries resulting from World War II. In preceding years, the belief was that healing of diseases came with rest and that nature would take its course. The development of the specialty of rehabilitation medicine (physical medicine and rehabilitation) was a joining of two concepts: (1) physical medicine with its special skills and tools and (2) comprehensive rehabilitation care. These two developments were led by Drs. Frank H. Krusen and Howard A. Rusk. By fulfilling an unmet need of a growing patient population, the field established a special identity with knowledge and skills specifically useful for a limited, defined patient population.

The practice of physical medicine and rehabilitation is known as physiatry. The American Board of Physical Medicine and Rehabilitation certifies physicians in physiatry.

The evolution of the field did not follow the standard concept of medical treatment with its emphasis on prevention and acute episodic care, but rather cut across many diseases and conditions frequently associated with disability, with the goal of restoration of the ability to function.

In this evolving field, physicians became the "captains" of interdisciplinary teams comprised of nurses and therapists who, in most cases, provide the services to the patient. The physiatrist's role is that of a coordinator of specialized therapies, and a manager of medical care. He or she relies on a number of non-physician specialists to provide much of the care to patients.

In recent years the value of rehabilitation medicine has been increasingly understood by other medical practitioners. Several factors have contributed to this popularity, including an increasing number of persons with diseases or injuries requiring medical rehabilitation, and acceptance by physicians in other medical specialties.

2. Freestanding Rehabilitation Hospitals

A rehabilitation hospital is a state-licensed hospital devoted exclusively to the delivery of medical rehabilitation. Prior to World War II, a few facilities in the country focused on treating people with specific disabilities such as polio, multiple sclerosis, and tuberculosis. These early facilities became comprehensive medical rehabilitation hospitals. They include, among others, Georgia Warm Springs, Georgia; Sister Kenny, Minnesota; and Casa Colina, California.

The major impetus for development of comprehensive rehabilitation hospitals came from military and Veterans Administration (V.A.) hospitals during World War II, particularly from the Army which developed a number of programs for wounded servicemen. People who had been wounded could improve more quickly through an active therapeutic program. These programs were initially put into the physical medicine departments at the V.A. hospitals and moved to private facilities in the 1950s.

Many physicians who were interested in rehabilitation in World War II and who went on to the Veterans Administration after the war, branched out to establish the earlier civilian freestanding rehabilitation facilities. Principle among these individuals were Dr. Howard Rusk, founder of the Rusk Institute, New York; and Dr. Henry Kessler, the founder of the Kessler Institute, New Jersey.

In the early 1950s, the United Mine Workers (UMW) included medical rehabilitation services in the health benefit package for its members. Injured miners were carried out of the mines on doors, and sent to Kessler, Rusk and other pioneering rehabilitation facilities in the country. There are presently approximately 100 freestanding rehabilitation hospitals concentrated primarily in the Northeast, Midwest and West Coast.

3. Rehabilitation Units in Acute Care Hospitals

As freestanding rehabilitation hospitals developed, rehabilitation also was introduced in acute care hospitals. A rehabilitation unit in an acute care hospital is a defined, organized unit devoted exclusively to medical rehabilitation.

In the 1950s, hospitals had physical therapy departments. As more physicians were trained in medical rehabilitation and more physical therapists entered the field, they brought their new skills and perspectives. As a result, these new units began to expand from being strictly concerned with physical therapy to include physiatry, rehabilitation nursing, occupational therapy, speech-language pathology, and social work. The Medicare and Medicaid programs and their payment for services were a primary factor in helping to develop rehabilitation units as well as providing payment for services provided in hospitals. After passage of Medicare and Medicaid in 1965, orthopedists, clinical psychologists, and others joined the units, creating the full complement of comprehensive medical rehabilitation services as they are known today. There are currently approximately 550 rehabilitation units.

4. **Outpatient Rehabilitation Programs**

Medical rehabilitation programs are also provided on an outpatient basis to appropriate patients by outpatient departments of hospitals, or by separate outpatient rehabilitation centers.

Outpatient facilities date from the early part of the century. The Institute for the Crippled and Disabled in New York was started during World War I. At the same time Virginia Upman Davis, OT, and fellow occupational therapists began the Curative Workshop of Milwaukee, and the Delaware Curative Workshop in 1944. The original emphasis was on reducing disability through occupational therapy, using such activities to strengthen patients as well as physical therapy and vocational rehabilitation, thereby integrating both the medical and vocational rehabilitation parts of the industry.

Starting in the 1940s, the Easter Seal Society and United Cerebral Palsy began small outpatient centers in various locations. Additionally, several insurance companies developed their own rehabilitation centers in the 1940s, such as Liberty Mutual of Boston, Massachusetts.

These small outpatient centers, like their inpatient counterparts, began to expand their services to include physical and occupational therapy, speech-language pathology services, rehabilitation medicine services, rehabilitation nursing, psychological and social services, vocational services and counseling.

By 1987, there were over 900 different outpatient rehabilitation program providers.

5. **Nursing Facilities**

Traditionally, nursing facilities have focused primarily on the needs of long-term care patients, be it chronically ill elderly persons or persons with long-term developmental disabilities. These facilities have provided some rehabilitation services but not at a very intense level, nor have they usually been formally structured or medically directed.

Over the past five to six years, however, there have been a few nursing facilities, primarily skilled nursing facilities, which have developed comprehensive rehabilitation programs, usually focused upon one specific disability area such as head injury. They are relatively new entrants in the rehabilitation field. Nine (9) such programs are now accredited by the Commission on Accreditation for Rehabilitation Facilities (CARF) for comprehensive inpatient rehabilitation.

6. Other Medical Rehabilitation Providers

Other types of facilities provide rehabilitation programs and/or services. Since rehabilitation is a growing field, other types of outpatient providers are expected. One such provider is the home health agency initially started by visiting nurses associations in many communities. Home health agencies generally provide a series of discrete rehabilitation services such as nursing, physical and occupational therapy. Community reentry programs and transitional living programs also provide rehabilitation therapies and services.

7. Vocational Rehabilitation Providers and Programs

The earliest forerunners to today's vocational rehabilitation programs were sheltered workshops first established in the 1930s. The first Goodwill Industry, Morgan Memorial in Boston, was founded in 1909.

The major impetus for vocational education and rehabilitation services stemmed from the need to serve those physically disabled in World War I. These programs focused on vocational evaluation, training or retraining, and placement.

State and Federal laws also supported putting persons with disabilities to work or back to work starting in 1917. They include workers' compensation laws, veterans and vocational education laws. The first Vocational Rehabilitation Act was passed in 1920. In 1943, the law was amended to include people with mental, as well as physical handicaps.

The problems of the mentally disabled were not as readily acknowledged or treated. The Kennedy and Johnson Administrations supported funds and programs for the mentally ill and retarded. The programs included funds for vocational assessment, training, and placement. By the mid 1970s, the emphasis in the Federal vocational rehabilitation programs was on providing vocational services to the persons with severe handicaps, and had recognized the needs of persons with developmental disabilities as well.

People in vocational rehabilitation programs are referred to as "clients" not as patients, as is the case in medical programs. Today, vocational facilities serve people with developmental disabilities, mental disabilities, cognitive disabilities, as well as those with physical disabilities. The emphasis is on evaluation, training, counseling and ultimately job placement. Placements may be directly into the employment market without additional services or through supported work with additional services such as counseling, transportation, etc. Such programs may be short term or long term.

Additionally, a number of joint medical and vocational programs exist which treat both aspects of the person's needs.

C. Conditions Necessitating Rehabilitation

Rehabilitation treats people of all ages. People become rehabilitation patients because of functional impairments resulting from trauma, disease, or congenital deformity. These incidents can lead to functional impairments, and rehabilitation addresses these problems. The diagnosis of a patient's condition does not drive the need for rehabilitation. The functional impairments do. Car accidents, sports accidents, work injuries, degenerative diseases, or birth defects (both physical and mental) cause the need for rehabilitation.

The most common conditions treated in a medical rehabilitation setting include, but are not limited to, back injury, spinal cord injury, head injury, fractures of the hip, amputations, multiple types of stroke, multiple types of arthritis, neurological diseases and trauma, and problems related to cancer, cardiovascular disease, pulmonary disease, chronic pain, and musculoskeletal diseases.

Among the elderly population, strokes, fracture of the femur, and arthritis are the three most common types of rehabilitation conditions. For younger ages, the most common conditions leading to rehabilitation are spinal cord injury and head injury due primarily to motor vehicle accidents or sports injuries. A number of centers specialize in treating pediatric cases for children who suffer from congenital birth defects, such as cerebral palsy, spina befida, the results of accidents, and other conditions.

As the population ages and as medical technology advances, the number of people coming into rehabilitation programs has been increasing. For example, in the area of head injury, the survival rate has increased from 50 percent to over 90 percent in the last decade, with a concomitant increase in the number of programs treating such individuals. Given that many survivors of head injuries suffer severe cognitive problems, existing rehabilitation programs are being adapted and new programs developed to recognize the different problems that this particular type of injury presents. In addition, people are living longer. Many of the very old (beyond 75) suffer from a chronic disease or disability and can benefit from rehabilitation programs to achieve or maintain functional ability.

Rehabilitation also helps individuals who have less dramatic types of injuries and can provide great benefit to people who may have suffered soft tissue injuries due to sport accidents, work injuries, or stiffness, or contractures due to old age and certain types of arthritis.

In general, medical rehabilitation seeks to rehabilitate/habilitate people so that they can live in the least restrictive, least costly environment at their highest possible level of independence.

III. PATIENT EVALUATION AND PLACEMENT

The patient characteristics described below must all be considered during the evaluation process in order to determine the most appropriate place for care (described in Chapter VI). The evaluation process requires expertise in medical rehabilitation to determine prognosis for recovery from illness or trauma. Therefore, all patients with functional impairments should enter the rehabilitation system for evaluation and treatment.

Ideally, initial placement of a patient in a rehabilitation program will be made through a collaborative process involving the attending physician in the acute care hospital, a physiatrist or physician with training and experience in rehabilitation (or otherwise qualified physician), qualified rehabilitation professionals, the patient, and/or the family. Often an initial placement must be made before the medical condition of the patient is completely stable. A complete evaluation of the patient to determine rehabilitation potential can normally be made only after admission to a rehabilitation facility. Subsequent progress through a spectrum of rehabilitation programs will reflect increasingly informed judgments about the patient's condition and rehabilitation potential.

The placement of a patient in the appropriate rehabilitation program should be determined by a physiatrist or otherwise qualified physician with the collaboration and assistance of other rehabilitation professionals. Placement should be made based on evaluation of the patient's medical status, functional status and social circumstances. Placement may also reflect program availability and services since, depending on the patient's geographic location, a full range of programs and providers may not be available. Under such circumstances, the best available program should be selected. Also, a patient's placement may change reflecting changing needs.

Presently, patient evaluation and placement cannot be reduced to a formula since the process involves the evaluation of a number of factors, few of which are completely quantifiable. Diagnosis and/or etiology of condition should not be the sole criteria for the selection of a rehabilitation program. Rehabilitation facilities utilize various scoring systems to represent functional status, including cognitive ability. Generally, medical status and social circumstances can only be described. In combination, these factors must be assessed by competent rehabilitation professionals and a judgment made as to the appropriate placement.

Patients with physical disabilities have changing needs at different times in the course of their recovery and these changing needs necessitate different types of care at different times in the process. The patient characteristics described in Chapter V are the variables required to make a placement decision.

IV. AVAILABILITY OF CARE

This monograph describes the various services and programs in medical rehabilitation. The ideal community would have high quality programs available at each point on the spectrum of care. Many areas of the country are deficient in some or all of such programs. However, rehabilitation facilities are attempting to meet the needs of their communities especially when appropriate referrals are made and followed. The availability of each program is critical to local physicians, the rehabilitation team, patients and families, and other consumers in making decisions about what type of care a person should receive, whether they should be sent out of the community to receive such care (if the family or payor concur), and the ultimate, optimal functioning of the patient. Another critical factor influencing placement is insurance or other coverage for rehabilitation. Many families may think they have appropriate coverage when they do not.

If a high level of care is available but not a lower one, it may be prudent for the patient to stay at the first level until able to function more independently. For example, if an intense medical program such as inpatient medical rehabilitation 2 (rehabilitation hospital or unit) has been completed and a inpatient medical rehabilitation 3 (atypical nursing home) program is needed but not available, the level 2 program should keep the patient until he or she is ready for outpatient care.

Some payors use guidelines that determine program coverage in various settings. In using the guidelines only, they do not take into account the actual availability of rehabilitation programs in the area. This results in patients getting little or no needed care and not being restored to their optimal functioning level. The most frequent example of improper denial is denial of admission to a rehabilitation hospital or unit without adequate care otherwise available. The patient may be sent to a custodial care nursing facility which has limited, if any, rehabilitation services available. The payor may not cover such services. If the patient were admitted to the rehabilitation hospital or unit, however, the patient could be restored to a higher functional level and ultimately discharged home, depending on social status.

Patients, families, and other consumers should become educated about which rehabilitation programs are available in their communities, and under what circumstances an insurer will allow a patient to go to the proper program level in another community, if needed.

To illustrate, there are approximately 100 freestanding rehabilitation hospitals and perhaps 550 rehabilitation units in the country. These tend to be located in larger communities. Comprehensive outpatient rehabilitation facilities providing comprehensive rehabilitation programs are growing in number, but as of this writing, number about 150. Day treatment programs are growing throughout the country. Many rehabilitation hospitals and units also provide organized outpatient rehabilitation services. Uneven distribution of services and programs is a very real issue and often poses difficult choices for patients and their families who must balance a desire for the most appropriate program with an interest in remaining near the patient's home.

V. CHARACTERISTICS OF A REHABILITATION PATIENT

A. Introduction

Frequently, patients who have the potential to improve their functional status are not identified by nonrehabilitation professionals. This is the phenomena of the invisible rehabilitation patient. This chapter discusses the characteristics of persons who can benefit from comprehensive medical rehabilitation programs or rehabilitation services. It discusses these characteristics of these persons generally and as part of the rehabilitation evaluation, and then groups them into broad, descriptive categories of patients who, because of these characteristics, may benefit from a rehabilitation program.

Often patients have both medical and nonmedical needs. Medically, they may be in a labile, (i.e., fragile) condition. In determining potential for rehabilitation, the person is evaluated by the physiatrist or another qualified rehabilitation physician and members of the interdisciplinary rehabilitation team to determine what programs or services are needed and at what intensity. The evaluation identifies the patient's status and problems in each area. These characteristics describe a patient's present status, but it may change at any time.

Based upon an evaluation, a person found to have potential to profit from rehabilitation will be referred to an appropriate program and may thereafter progress to other programs as his or her condition improves. Patients requiring the most intensive program of rehabilitative care will be found in freestanding rehabilitation hospitals and units of acute care hospitals. Typically, patients are referred to these sites after treatment in an acute care hospital to achieve medical stability from an accident or disease. The rehabilitation hospital program is, however, provided to patients whose medical condition may be still fragile, who have a serious impairment and who require constant physician involvement and 24-hour nursing care. Patients admitted to these settings will generally be served for a period of weeks or months, depending on the nature of the disability, medical condition and, in some cases, availability of alternatives for treatment. Average lengths of stay in such an acute rehabilitation setting are usually in excess of 30 days, according to a NARF study. The duration of treatment may be much longer for very complex cases, such as those involving spinal cord and head injuries.

Patients progress from the rehabilitation hospital or unit to independent living or a less intense rehabilitation program or rehabilitation services. A patient whose medical condition and ability to function is such that an intense program is no longer required may go home and may continue to receive a comprehensive rehabilitation program or individual services from a home health agency, comprehensive outpatient rehabilitation facility, outpatient department of a hospital, or day treatment program. Some home health agencies provide rehabilitation services to patients who have been discharged to their homes or another residential environment. Comprehensive outpatient facilities provide comprehensive rehabilitation programs similar in scope and nature to those found in hospitals and units but to patients who are at home or in another residential setting who come to the facility for treatment.

If the patient cannot go home but needs a less intense level of programs or services, they may go to a nursing home. Typical nursing homes generally provide limited individual rehabilitation services to their patients.

A rehabilitation patient will enter this system of rehabilitative care depending on his or her condition and the availability of services in the area and progress to the point of maximum improvement. For example, depending on the patient's medical condition, a person with a stroke would likely be medically stabilized in an acute care hospital, transferred to a rehabilitation hospital or unit for intensive comprehensive rehabilitation and discharged to home when able to function independently or with family assistance and perhaps some outpatient rehabilitation services. A patient may also be transferred to an atypical nursing facility which offers a comprehensive medical rehabilitation program when a less intense program is required for an individual still requiring inpatient care. In cases where the patient is medically stable and reasonably independent at the point of discharge from the acute care hospital, he or she may be discharged to home and rehabilitation may proceed on an outpatient basis. The patient might continue to receive a comprehensive program through an outpatient department of a hospital or a freestanding comprehensive outpatient program. If such intense, coordinated services were no longer required, a single service, such as physical therapy or speech therapy, might be appropriate.

B. General Characteristics

The following summarizes factors in a patient's rehabilitation evaluation.

1. Rehabilitation Potential

Each rehabilitation candidate is presumed to have potential to become more independent.

The evaluation defines such rehabilitation potential and fashions a rehabilitation program to fulfill it. Rehabilitation potential is a judgment made by trained rehabilitation professionals that a patient with a disability can lessen the impact of that disability through training or treatment. The patient will achieve this potential within a generally defined time period at a reasonable cost and application of available resources.

When a patient has made the gains possible in one program, the patient may move to the next program but sometimes may need to move backward if problems arise.

2. Health Status

Health status is a major factor in determining an appropriate program. Often rehabilitation patients have survived immediate life-threatening episodes. They have impairments which may result in more severe functional limitations if a rehabilitation program is not provided. Medical needs may range from requiring constant, close, active medical management to needing minimal medical attention.

The patient's nursing needs, ranging from medical/surgical nursing and inpatient rehabilitation nursing, to services from a home health aide, are also major factors in determining the appropriate program.

3. Functional Status

Improved function is the goal of rehabilitation programs. Rehabilitation permits patients to perform everyday activities comfortably and/or expeditiously. The degree to which they can or cannot perform these activities safely and effectively, the amount of supervision and/or assistance required will assist in determining the most suitable program. These factors include:

a. Mobility

Mobility encompasses a patient's ability to move from one place to another. Moving from bed, walking, using stairs, using a wheelchair, crutches or walker; and transferring from bed to chair to toilet, tub or shower are the areas where mobility is tested. The need for assistance or supervision, use of a wheelchair, crutches or walker, is also a factor. The environment in which the person lives, i.e., whether there are architectural or other environmental barriers to mobility, is also important.

b. Activities of Daily Living (A.D.L.)

Basic ADL includes a patient's ability to drink or eat, bathe or wash, groom and manage bowel and bladder functions. Advanced ADL includes basic meal preparation, money management, household tasks, etc. Any need for assistance or supervision is a major factor in determining services required by a patient.

c. Safety

Safety may be a medical or a personal judgment issue. Medical safety relates to acquired secondary complications which can potentially cause or worsen contractures, bed sores, urinary tract infections, deep vein thrombosis or other problems. Personal safety considers the patient's ability to solve problems or manage needs in a physically and mentally safe manner and may involve cognitive abilities as well. When safety is a problem, the person may need supervision or assistance from another person.

d. Cognition

Cognition is the patient's ability to think, to be aware of, and to understand what is going on in his environment. Difficulties with cognition are usually associated with head injury and stroke, as well as other neurologically related conditions.

e. Behavior

Behavior relates to the patient's ability to conduct himself in a socially acceptable manner. Behavioral problems may result from injury to certain parts of the brain or emotional responses to the disabilities.

f. Communication

Communication is the person's ability to express himself verbally, in writing or by gesture or sign, and to hear, or otherwise understand, what is being conveyed with or without assistance.

g. Psycho/Social

Psycho/social status relates to the patient's self esteem given a change in body image and the desire to interact with people.

4. Social Status

Social status refers to the patient's home situation, and the availability of family members or others who can lend support as needed. Social status is a factor in determining entrance into certain programs and services.

5. Vocational/Educational and Retirement Status

Vocational status includes a patient's work status prior to the disability; the ability to return to the same position or other position with or without some modification and training, and whether training may enhance the ability to work. It also encompasses the patient's retirement status and level of activity and personal goals during retirement.

Educational status includes whether the patient was in school prior to the incident; can be expected to return to regular school; or will need to return to school for different educational/professional or technical training.

C. Rehabilitation Patient Groups

Eight (8) patient groupings are discussed below, from Group 1, highest degree of medical and nursing needs to Group 8, lowest medical and nursing needs.* These categories describe the types of patients who can benefit from various types of rehabilitation programs or services.

1. Group 1

These patients are the most severely ill patients immediately post trauma or disease. Their rehabilitation potential is most uncertain at this stage of recovery. Good rehabilitation techniques during this period can improve potential for recovery as well as prevent secondary complications.

Health Status

Group 1 patients have severe abnormalities of one or more body systems secondary to disease or trauma. The extent of their pathology tends to change significantly over hours or days. They usually demonstrate change towards improved medical/clinical status, but often slow progression in their pathology. They are highly vulnerable to significant secondary involvement of additional body systems and to major complications of already involved systems. These complications are likely to produce changes which occur rapidly, sometimes within minutes. These patients remain highly vulnerable to death or permanent system compromise unless homeostasis (a physically steady state) is developed and maintained through appropriate medical and nursing involvement.

Functional Status

The patient is dependent in multiple functional areas. Total physical care usually is required by virtue of the person's physical disability and/or acute medical condition. Eventual residual physical impairment is unknown at this time.

Social Status

The patient's family or others are generally very involved emotionally during the critical phase. Their focus is typically on the patient's survival, with little comprehension of the potential long-term implications.

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* These groups were developed by the industry based Task Force which drafted the document rather than being research based.

Vocational/Educational Status

The patient may have potential to return to work, an educational setting, or, if retired, to an active, meaningful retirement, but this potential cannot be completely evaluated at this time.

2. **Group 2**

These patients may still have serious medical problems. However, health status is sufficiently resolved to shift the primary focus of care to rehabilitation. There is a reasonable expectation that rehabilitation potential exists and that a comprehensive rehabilitation program will improve functional status.

Health Status

Group 2 patients have significant abnormalities of one or more body systems secondary to disease or trauma. The extent of their pathology tends to change significantly over days. They almost always demonstrate change towards improved status. They may develop secondary involvement of additional body systems or complications of already involved body systems. Some of these complications may produce rapid changes (within minutes) but others may develop over hours or days. These patients remain significantly vulnerable to death or permanent system abnormality unless homeostasis is developed and maintained through appropriate medical and nursing involvement. While health status continues to be abnormal, the patient now needs rehabilitation to enhance functional status. The patient's medical problems may also require daily physician management by a general or attending physician in addition to the physiatrist or otherwise qualified rehabilitation physician.

Functional Status

The patient is dependent in multiple functional areas requiring coordinated efforts of multiple rehabilitation specialists to learn or relearn how to meet daily needs. The patient is expected to be able to tolerate, participate in and benefit from sufficiently intense therapies and services and expected to show functional improvements in relatively short periods of time, generally at least every two weeks. However, from time to time medical problems may temporarily interfere with the patient's ability to tolerate and benefit from therapies. The patient continues to improve his or her status toward established goals. The person's dependency prohibits living at home. The risk of increased dependency due to receiving less intense care exists.

Social Status

The patient's family or others, even if they are present and willing supporters, cannot meet the patient's current physical and psychosocial needs. They will require education to help the patient in these areas. The presence, desire, and ability of the family and others to help the patient and be educated as to his/her needs is important.

Vocational/Educational Status

The patient may have potential to return to work, an educational setting, or, if retired, to an active, meaningful retirement, but this potential cannot be completely evaluated at this time.

3. **Group 3**

The patient is more medically stable but continues to have medical complications related to the impairment. The underlying medical condition is still serious and requires continued medical involvement.

Health Status

Group 3 patients have significant abnormalities of one or more body systems secondary to disease and trauma. The extent of their pathology remains essentially stable. They are unlikely to develop secondary involvement of additional systems or complication involving already involved systems. These patients remain somewhat vulnerable to permanent system compromise unless homeostasis is maintained through appropriate medical and nursing involvement.

Functional Status

The patient is dependent in multiple areas. He or she requires the coordinated efforts of multiple rehabilitation specialists to learn or relearn methods to meet daily needs. The patient is expected to be able to participate in and benefit from a number of coordinated therapies and services and is expected to show functional improvement generally more than every two weeks. The patient continues to progress in improving his or her functional status toward established goals. The patient's dependency prohibits living at home at this time. The rate of change and improvement is slower than for a patient in Group 1 or 2.

Social Status

The presence, desire, and ability of the family and others to help the person and be educated as to his/her needs is important. At this point, the patient's family or others are willing supporters, but cannot meet his/her current physical and psychosocial needs and require education to help the patient in these areas.

Vocational/Educational Status

The patient may have potential to return to work, an educational setting, or, if retired, to an active, meaningful retirement and may have a prevocational/educational assessment at this time.

4. **Group 4**

These patients are moderately ill, having stabilized or markedly slowed in their recovery from trauma or disease. Their physical impairments and/or disabilities may benefit from selected rehabilitation services to prevent complication and improve their limited functions. This group includes long-term chronic care patients. Rehabilitation services with help preserve existing functional ability and help prevent complications and restore function.

Health Status

Group 4 patients have residual abnormalities of one or more body systems secondary to disease or trauma. The extent of their pathology remains essentially stable. They are unlikely to develop secondary involvement of additional systems or complications of already involved systems. These patients remain significantly vulnerable to permanent system compromise unless homeostasis is maintained through appropriate medical and nursing involvement.

Functional Status

The patient may be dependent in several areas. He or she requires some rehabilitation services to learn or relearn methods to meet daily needs; is expected to be able to participate in and benefit from a limited number of therapies and services, and is expected to show improvement or prevent deterioration of current functional levels. The patient's dependency prohibits living at home. Hence, the rate of change and improvement is slower than for a patient in a Group 1, 2 or 3 program. A more intense program would not increase the patient's rate of change.

Social Status

The presence, desire, and ability of the family and/or others to help the patient and be educated as to his/her needs is important. At this point, the patient's family or others are willing supporters, but cannot meet his/her current needs and will require education to help the patient in these areas.

Vocational/Educational Status

The patient may have potential to return to work, an educational setting, or, if retired, to an active, meaningful retirement, but it is unlikely.

5. Group 5

These patients are moderately ill, having stabilized or markedly slowed in their recovery from trauma or disease. Their physical impairments and/or disabilities may benefit from selected rehabilitation services to prevent complications and improve their limited functions. The family or others can care for the majority of their nursing needs and personal care. Group 5 patients may need rehabilitation services at home because of their lack of ability to travel. Many of these patients are served on an outpatient basis at home with family or others' support and certain needed services are available. Rehabilitation services will help restore more independent function, preserve existing functional abilities, and/or help prevent complications.

Health Status

Group 5 patients have residual abnormalities of one or more body systems and severe functional deficits. The extent of their pathology remains essentially stable. They are unlikely to develop secondary involvement of additional systems or complications of already involved systems. They remain vulnerable to system compromise unless homeostasis is maintained through appropriate attention to nursing needs and therapeutic intervention.

Functional Status

The patient may be dependent in several areas. The patient requires some rehabilitation services to learn or relearn how to meet daily needs, and is expected to be able to participate in and benefit from a limited number of therapies and services. From the therapies and services, the patient is expected to show functional improvement, avoid deterioration of current functional levels and/or prevent complications.

Social Status

The family or others are able to meet the patient's daily needs at home, provided that other professional services are available.

Vocational/Educational Status

The patient may have potential to return to work, an educational setting, or, if retired, to an active, meaningful retirement. This can be determined by periodic vocational, educational, recreational evaluations with a rehabilitation plan developed subsequent to the evaluations.

6. Group 6

The patient is medically stable enough not to require inpatient care, but requires regular physician attention to monitor and treat the consequences of the impairment(s) to the organ systems and to prevent complications of the primary or secondary diagnoses.

The patient continues to require rehabilitation nursing services to monitor, educate, and pursue new skills in the rehabilitation program.

From a social and functional standpoint, there are several subsets to this group. These are based on the availability of adequate family, social or community services to help the patient live outside the inpatient setting. These patients also have differences in their functional status and different levels of ability in various aspects of their functional status.

Health Status

Group 6 patients have persistent abnormalities of one or more body systems secondary to disease or trauma. Their pathology remains stable and they are generally unlikely to have secondary involvement or complications if homeostasis is maintained through appropriate medical, nursing and attendant care as indicated. Their pathology remains essentially stable and they are unlikely to develop additional complications. They may continue to have needs which are met by appropriately trained family or others in their residential setting.

Functional Status

Subgroup A. The patient is dependent in several areas and is expected to tolerate, participate and benefit from intense, coordinated multiple therapies and services, and is expected to show improvements against specified goals in reasonable periods of time. He or she requires a coordinated rehabilitation program to learn or relearn how to meet daily needs.

Subgroup B. The patient's total functional ability is not at the level anticipated for his or her rehabilitation goals and can improve with prescribed rehabilitation services.

Social Status

Subgroup A. Patients need external, knowledgeable support in one or more areas with which a patient may move toward more independent functioning. With this support, the patient may move into transitional, residential or independent living. This support may be provided by an appropriately trained family, community support, transitional living center or other supportive unit or services.

Subgroup B. The patient may be able to live independently with or without supportive services at home.

Vocational/Educational Status

The patient may need a prevocational, educational or recreational assessment of his/her potential to return to a work setting, school, or retirement activities. Vocational and educational status prior to the disabling incident also influences whether such assessment(s) are needed. The patient may be able to participate in a vocational, educational or recreational plan, testing, and possibly training or education.

7. **Group 7**

The patient's medical condition is stable but he or she may be more prone to medical complications than the general population. Routine evaluations are needed to assure that functional status is maintained and to assess the requirement for continued therapy.

The patient does not require regular nursing services. A personal care assistant may be needed to help with activities of daily living.

Patients in this group may not require complete assistance in mobility or activities of daily living, but may lack mental, cognitive, behavioral and communicative ability and cannot maintain himself or herself in a manner that assures physical safety alone.

Health Status

Group 7 patients continue to have abnormalities of one or more body systems due to disease or trauma. Their pathology remains stable and they are generally unlikely to have secondary involvement or complications if homeostasis is maintained through appropriate medical, nursing and personal aides' involvement, if needed.

Functional Status

The patient is dependent in significant functional areas. Psychosocial needs may outweigh medical needs. The person is expected to participate in and benefit from a coordinated program of services to reintegrate into the community.

Social Status

Patients need knowledgeable, external emotional and cognitive support in one or more areas (physical, emotional, cognitive, transportation, housing) without which the patient may not be able to move toward more independent functioning, transitional, residential or independent living. This may be provided by an appropriately trained family, community support or transitional living center or other supportive unit based on availability and the patient's functional status.

Vocational/Educational Status

The person may participate in a vocational or educational assessment of the ability to return to a work setting, school, or retirement activities and programs involving, as needed, vocational training, work adjustment, placement services, recreation and education.

8. **Group 8**

The person is medically stable, not at risk, and may have had a good recovery. The person may require only routine evaluation to assure that functional status is maintained and to assess the need for therapy. The person is responsible for identifying his/her own medical problems requiring help and for scheduling appointments.

Health Status

Group 8 patients may or may not still have residual impairments or one or more body systems due to disease or trauma. Pathology remains stable. The risk for secondary involvement and complications remains low as long as the patient follows any prescribed program of personal care.

Functional Status

The patient can perform at all functional activities within his or her capacity in spite of the impairments. This may include the use of a personal care attendant.

Social Status

The person is living independently, either on his or her own, with family, with others, or in an alternative living setting.

Vocational/Educational Status

The person may have residual functional problems which interfere with vocational, educational, retirement activities. The person can participate in vocational and/ or educational programs, including assessment, a vocational plan, vocational training, work assimilation, work adjustment and placement services. The person may be employed in a work program specific to his or her needs while continuing to see a vocational rehabilitation counselor. The person can participate in education courses, or recreation courses to help achieve an active, meaningful retirement.

Group	Health Status Summary
I	• Immediate Post-Trauma with Changing Pathology • Vulnerable to Significant Secondary Involvement • High Level of Medical Involvement • Changing Rapidly
II	• Continues to Have Serious Medical Problems • Continues to Have Changing Pathology • Less Vulnerable to Significant Secondary Involvement • Requires Daily Physician Management
III	• Increased Medical Stability • Unlikely to Develop Secondary Involvement • Needs Continued Medical Attention
IV	• Medically Stabilized but Still Moderately Ill • Unlikely to Develop Secondary Involvement of Additional Systems • Needs Medical Involvement to Prevent Compromised System
V	• Moderately Ill • Unlikely to Develop Secondary Involvement of Additional Systems • Some Medical Involvement Needed
VI	• Medically Stable • Generally not a Risk to Develop Secondary Complications • Physician's Involvement Needed Only Intermittently to Prevent Complications
VII	• Medically Stable • Generally not a Risk to Develop Secondary Complications • Psychosocial Needs May Outweigh Medical Needs
VIII	• Medically Stable • Very Low Risk for Secondary Complications Follow-Up • Prescribed Medical Program • Routine Medical Evaluation

VI. CHARACTERISTICS OF MEDICAL REHABILITATION PROGRAMS AND SERVICES: WHAT IS A PROGRAM? WHAT IS A SERVICE? WHAT MAKES THEM DIFFERENT?

This chapter describes the differences between comprehensive medical rehabilitation programs and rehabilitation services and describes different types of rehabilitation programs and services. The distinguishing characteristic of a rehabilitation "program" as opposed to a rehabilitation "service" is that a program encompasses the coordinated, interactive, goal-directed integration of services under the direction of an interdisciplinary team.

This team is responsible for assessing a patient's progress within specific time frames, achieving the rehabilitation program's objectives, providing additional clinical care when indicated, and regularly measuring the patient's progress. Each professional team member's expertise is built on and coordinated with other team members. This interaction creates the appropriate therapeutic milieu of a rehabilitation program. For example, a patient's physical therapist (PT) will inform the occupational therapist (OT) about reinforcing the PT part of the program through the OT modalities and vice versa. Both professionals alert the rehabilitation nurse to the patient's progress and goals so that there is a consistent and coordinated approach. Because of such transfer and reinforcement in a comprehensive program, the whole is greater than the sum of the individual services provided.

A. Rehabilitation Program Characteristics

A potential program patient may be self-referred, referred by the facility, physician, agency, payor, or case manager for evaluation.

Rehabilitation programs may include a wide range of services. They are goal oriented, including short- and long-term goals. A program is medically prescribed.

Generally, once a person is admitted to a program, as noted above, it starts with an evaluation performed by a physiatrist or otherwise qualified rehabilitation physician and therapists with training and experience in rehabilitation. The evaluation identifies the patient's rehabilitation potential by taking into account the medical/nursing, functional, sociological, vocational, educational and retirement characteristics of the patient. To the degree possible, patients and families should plan and participate in the patient's rehabilitation program.

Programs involve a coordinated approach by an interdisciplinary team which develops an integrated plan for treatment of services with mutually agreed upon treatment goals and process, led by a physiatrist or otherwise qualified physician. They are oriented to outcomes which achieve independence for the patient. Rehabilitation programs generally involve rehabilitation nursing as well as medical nursing.

The treatment program incorporates the medical, functional, sociological, and vocational, educational and retirement factors determined by the evaluation. Rehabilitation programs are monitored through team conferences which are managed by an individual with training and experience in medical rehabilitation and the interdisciplinary team approach. Programs involve the family whenever possible. As the treatment program is developed, the team works with the patient and family on discharge planning.

Usually during the course of treatment there is a program manager within the facility who, with other staff involvement, bears primary responsibility for the total program of the patient, its coordination, conduct and follow-up activities. This is usually the same person throughout the program. Also, the patient's program may involve a case manager who, if from the facility, may work with a case manager from the payor.

A number of disability specific programs are also being developed in rehabilitation facilities as subsets of a general comprehensive rehabilitation program described above. These specific programs include head injury programs, spinal cord injury programs, stroke, and pain management programs among others. In these programs, the rehabilitation physicians, nurses and therapists need to have special training to treat these particular patients, and experience in seeing a number of patients with these disabilities since they present unique challenges.

B. Rehabilitation Services Characteristics

A rehabilitation service is provided by an individual discipline. Each discipline provides its own patient evaluation for that particular service without coordinated treatment goals, process, or information from other disciplines.

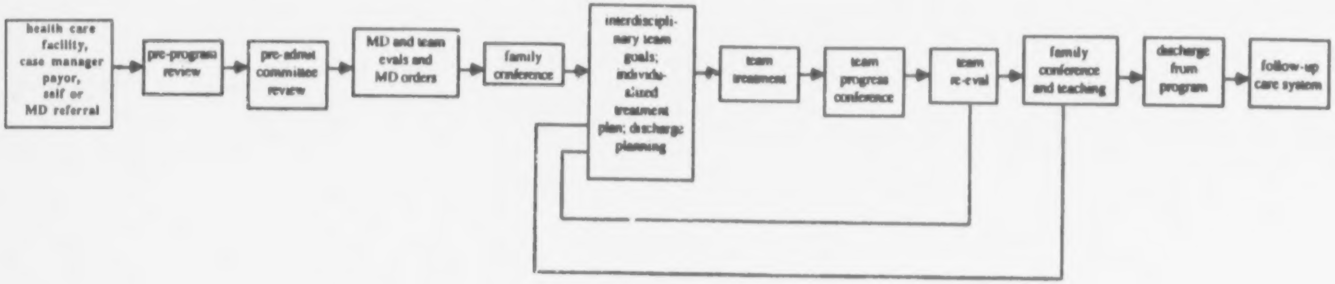
Rehabilitation services may begin while the patient is in the acute care hospital, prior to being transferred to a rehabilitation program. Following discharge from a rehabilitation program, an individual service may be the only requirement for completing the patient's rehabilitation plan.

While comprehensive medical rehabilitation programs generally include a number of coordinated rehabilitation services, there are times when services of an individual discipline are appropriate. Such services (when not part of a program) are delivered by an individual discipline such as a physical therapist or speech/language pathologist or in concert with other services, but are not formally coordinated.

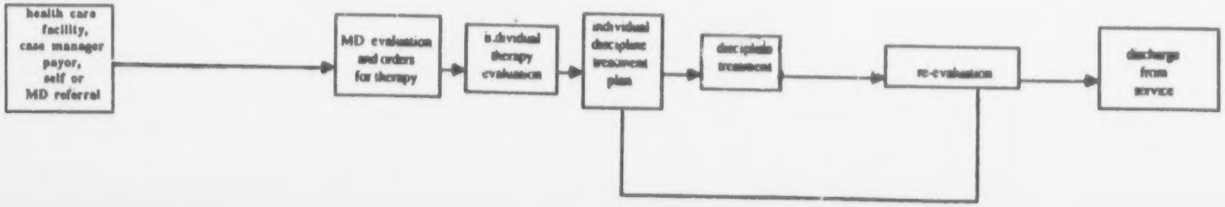
When a patient receives services from more than one discipline, therapists may communicate through informal channels in contrast to a team conference which occurs in a program. Services may be evaluative, diagnostic, and/or treatment oriented. Evaluations and treatments are performed by or under the direct supervision of a professional with appropriate credentials. Treatment plans are directed toward specified functional goals.

Services are appropriate when (1) the patient's acute condition is of primary importance and a program is premature; (2) the patient had an acute problem that does not appear to have long-term disabling effects; or (3) following participation in a program, the patient needs only specific services to address a few functional areas. For example, it is not unusual for a person with a stroke to continue to receive speech/language pathology services after the rehabilitation team members have discharged the patient from other therapies.

REHABILITATION PROGRAM PROCESS


health care facility, case manager payor, self or MD referral
pre-program review
pre-admit committee review
MD and team evals and MD orders
family conference
interdiscipli-nary team goals; individu-alized treatment plan; discharge planning
team treatment
team progress conference
team re-eval
family conference and teaching
discharge from program
follow-up care system

REHABILITATION SERVICE PROCESS


health care facility, case manager payor, self or MD referral
MD evaluation and orders for therapy
individual therapy evaluation
individual discipline treatment plan
discipline treatment
re-evaluation
discharge from service

C. Rehabilitation Programs and Services

The various types and intensities of rehabilitation programs and services may be viewed as forming a spectrum of care. Comprehensive medical rehabilitation programs may be provided at many levels in the spectrum of care. A person may enter and exit this spectrum at any point based on the individual characteristics described in Chapter V. Programs in the spectrum of care are composed of individual service components. The list outlined below reflects a spectrum of programs and services, starting from those requiring a high level of medical involvement to the least intense programs, reflecting the patient's level of independent functioning. It reflects the spectrum of care presently available. However, the rehabilitation field is changing rapidly and additional points on the spectrum will emerge.

1. Inpatient Medical Rehabilitation 1 - Rehabilitation Components in Acute Care

This program includes all those persons who survive transport to the hospital after an injury or illness and who are acutely ill and/or medically unstable.

The program has surgical and diagnostic capabilities for management of acute traumatic injury or illness, e.g., radiology, lab, and surgery. It includes a variety of medical specialties available for consultation and primary care, e.g., internal medicine, orthopedics, neurology, surgery, rehabilitation, and pulmonology. The primary emphasis in this program is on stabilizing the patient's medical/surgical needs and survival. Rehabilitation components are provided, for example, passive exercises, positioning and splinting to prevent contractures and complications, and speech/language pathology to assist in swallowing.

o **Where Does This Occur?**

Short-term general acute care hospitals, general medical/surgical wards, trauma centers and intensive care units may offer these components. Many communities have designated trauma units designed to provide early critical care to trauma victims.

o **Components**

Medical and Nursing Services

At this acute level, care is provided by a multidisciplinary team of specialists which include physicians, critical care nurses, respiratory therapists, dieticians, pharmacists, and sometimes rehabilitation clinical professionals.

A multidisciplinary, critical care team including rehabilitation professionals is essential to manage the patient's unstable condition. Critical care nurses generally provide 10 to 16 hours of nursing care per day. Continuous physician management is achieved with a minimum of daily visits and frequent communication with nursing staff.

This level of care requires a high level of nursing care including 24-hour medical and or surgical nursing. Physician involvement is continuous and is usually provided by a team of specialists.

Therapies and Services

Rehabilitation therapies and services, such as occupational therapy, physical therapy, and speech/language pathology services are initiated to maximize the patient's potential for recovery. Therapy services may be provided consistent with the patient's tolerance. The major focus is to prevent or minimize secondary complications; however, rehabilitation services also have a positive effect on the speed of recovery.

Plan of Treatment

The plan of treatment is established and managed by the physician and acute care staff. The plan is revised frequently, as the patient's condition is very fragile, and may change on a daily or even hourly basis.

2. Inpatient Medical Rehabilitation 2 - Rehabilitation Hospitals and Units

These comprehensive inpatient medical rehabilitation programs are for persons who are still medically fragile, have severe functional impairments, and need the support of a medical facility. They have potential for improving their functional abilities at regular intervals.

Such programs provide close medical supervision by a physiatrist or otherwise qualified rehabilitation physician. Such physicians are available on a 24-hour basis. Additionally, the program provides 24-hour availability of registered nurses with specialized training and experience in rehabilitation. A program provides at least 8.5 hours of rehabilitation nursing and therapies such as physical therapy, occupational therapy, speech, and psychosocial services daily.

The program includes an interdisciplinary team consisting of the physician, rehabilitation nurse and therapists. The interdisciplinary team provides the patient's program through a coordinated program of care that is documented. Team conferences are held at least every two weeks to assess the patient's progress, problems impeding progress and assessing the initial rehabilitation goals.

A program of this nature provides preadmission screening for a patient to determine if a patient is likely to benefit significantly from an intensive, comprehensive rehabilitation program. The preadmission screening may take place in the rehabilitation facility or the facility in which the patient is currently residing.

After screening, the program provides an extensive professional review of the patient's condition by the physiatrist or otherwise qualified physician and the interdisciplinary rehabilitation team. Such assessments usually require between 3 to 10 calendar days, but on occasion may require more. Even if a patient received therapies prior to admission, an initial assessment period is reasonable and necessary.

This type of program is necessary for a patient who requires a more coordinated, intensive program of multiple services than generally found in other rehabilitation programs. A patient who has one or more conditions requiring intense, interdisciplinary rehabilitation care or who has medical complications in addition to the primary condition so that the continuing availability of a physician is required to insure safety and treatment, requires this type of rehabilitation program.

The goals of the program assume a reasonable expectation of improvement for the patient measured against his or her admitting condition. The program sets realistic goals for patients in view of their status. It continues until further progress towards the established goals are achieved and the patient goes home or progress continues at such a slow rate that the patient can be served better in another facility. It is at this time and in this program that major decisions about the patient's future placement are made. In making this determination the team looks at the degree of improvement that has occurred and the type of program required to achieve further improvement.

The program may include occasional home visits and trips into the community as part of the therapeutic program to determine whether the patient should continue to stay in the program. Such visits and trips are used to test the patient's ability to function outside the institutional setting and to assist in discharge planning for the patient. Discharge planning is a process which involves the family, the patient, the treatment team, and may include the payor.

- **Where Does This Occur?**

  These comprehensive inpatient medical rehabilitation programs usually are found in freestanding rehabilitation hospitals or rehabilitation units of general acute care hospitals. These programs are usually accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) for comprehensive inpatient rehabilitation programs, the Joint Commission on Accreditation of Healthcare Organizations for rehabilitation, and/or the American Osteopathic Association.

  Currently, there are nine (9) skilled nursing facilities with CARF accreditation for inpatient rehabilitation programs. This is an exception, not the norm. Over 50 percent of them are for persons with head injuries.

- **Components**

  Medical and Nursing Services

  Close, daily, on-site, active medical management and supervision by a physiatrist or otherwise qualified rehabilitation physician, and daily presence of this physician, is provided as well as 24-hour rehabilitation nursing in addition to skilled medical/surgical nursing. Other medical specialists are available as needed.

  Therapies and Services

  Intensive, coordinated services and therapies are provided as outlined in the plan of treatment. A minimum of 8.5 hours per day for a minimum of five days a week of rehabilitation nursing, therapies, and services are delivered by an interdisciplinary team. CARF requires a minimum of 5.5 nursing hours per day; Medicare requires a minimum of 3 hours of specified therapies a day, five days a week.

  Plan of Treatment

  A plan of treatment is established and managed by the physiatrist or otherwise qualified rehabilitation physician and the interdisciplinary team. It outlines the person's anticipated goals, type, amount, frequency, and duration of services. It is reviewed by the team every two weeks and revised as necessary. It is also revised if there are other changes in the person's condition.

3. Inpatient Medical Rehabilitation 3 - Atypical Nursing Homes

These comprehensive inpatient medical rehabilitation programs are for people who are sick and disabled enough to require institutional support. These people have the potential for significant gains in functional improvement but improvement will occur at a rate slower than every two weeks.

This program has similarities to inpatient hospital-based comprehensive rehabilitation programs but is less intense. It provides a rehabilitation evaluation at the time of referral to the rehabilitation facility, medical management by a physiatrist or otherwise qualified rehabilitation physician, and 24-hour rehabilitation nursing care and an interdisciplinary treatment team.

- **Where Does This Occur?**

  This program is most typically found in a nursing facility that has a comprehensive inpatient rehabilitation program. This program may be delivered also in a rehabilitation hospital or unit when an appropriately organized nursing facility is not available.

- **Components**

  Medical and Nursing Services

  A physiatrist or otherwise qualified rehabilitation physician provides the medical management of the patient and provides those services at least once a week; however, these services are available 24 hours per day. Rehabilitation nursing in addition to skilled medical/surgical nursing is provided 24 hours a day.

  Therapies and Other Services

  Coordinated therapies and services are provided as outlined in the plan of treatment. The total hours of rehabilitation nursing, therapies, and services delivered by an interdisciplinary team per day is at least five hours per day. More intensive therapy and services do not make this patient's rehabilitation happen faster.

  Plan of Treatment

  A plan of treatment is established and managed by the physiatrist or otherwise qualified rehabilitation physician in consultation with other members of the interdisciplinary team. The plan outlines the patient's anticipated goals, type, amount, frequency and duration of services, and is reviewed and revised by the team at least once a month. It is also revised if there are changes in the patient's condition.

4. Inpatient Medical Rehabilitation 4 - Typical Nursing Homes With Rehabilitation Services

Many nursing homes currently provide only intermittent, individual rehabilitation services which focus on preventing deterioration of function or improving a patient's level of function, as opposed to providing a comprehensive program.

They work with patients to restore function at a very slow rate. These patients have rehabilitation needs, but rehabilitation is not the primary focus. An evaluation at referral, medical management by a physician, and nursing care are required.

Services may be delivered periodically as often as three times per week or as little as once a month. In some instances, services are not on a one-on-one basis, delivered by a therapist to one patient, but may consist of group sessions with a therapist and an aide working with a group of nursing home residents in an exercise course of other general activity that is not specific to each patient's condition.

- **Where Does This Occur?**

  These services are found in general nursing homes which do not have comprehensive rehabilitation programs. They are focused primarily on treating chronically ill patients with long-term medical and nursing needs.

- **Components**

  Medical and Nursing Needs

  These patients require physician services and review once a month, 24-hour nursing care and 24-hour availability of a physician.

  Therapies and Services

  Typically these programs provide individual rehabilitation therapies and services only by physician's prescription as need dictates.

  Plan of Treatment

  A plan of treatment is established and managed by a physician outlining amount, frequency, and duration of services. It is reviewed monthly and revised as needed.

The programs described below are all outpatient rehabilitation programs. They include:

5. Rehabilitation Programs and Services Delivered in the Home

Home rehabilitation programs are also available. A home health program is for people who are relatively medically stable and require a physiatrist's or otherwise qualified rehabilitation physician's attention only periodically, but have not realized the goals of their rehabilitation plan. A physiatrist or otherwise qualified rehabilitation physician performs an evaluation in coordination with the interdisciplinary team, establishes a plan of treatment, and monitors medical stability. Home health rehabilitation programs are delivered in the patient's home because the patient has an impairment or medical condition that prevents him or her from going to an outpatient facility. In some instances when familiar surroundings enhance the therapy, home care may be appropriate.

Both comprehensive medical rehabilitation programs and rehabilitation services may be delivered in the home. Generally, home programs deliver rehabilitation services, however, the nursing needs of the patient may dominate. Atypical home programs include a comprehensive medical rehabilitation program. These rehabilitation programs may not be as involved as a comprehensive medical outpatient rehabilitation program since, for example, all the equipment may not be brought into the home but they do provide for the patient's needs. Whether a home program or service is delivered will depend on local availability and the patient's needs for multiple services or an individual service.

o Where Does This Occur?

Typically, these programs are delivered primarily through home health agencies, hospital outpatient departments or outpatient rehabilitation facilities. Candidates for home programs may be referred from acute care hospitals, an inpatient rehabilitation, program 2 or program 3, or day rehabilitation programs. More often, home programs provide services. Emerging home rehabilitation programs provide a rehabilitation program.

o Components

Medical and Nursing Services

In a program, the physiatrist or otherwise qualified rehabilitation physician evaluates the patient, establishes and manages the plan of treatment, and reviews and evaluates it and the patient at least every other month. The physician sees the person as needed but not less than bimonthly. Rehabilitation nursing is provided to monitor stability and provide education for the patient and/or family/others.

When services are required, the physician evaluates and refers the patient for the needed nursing and therapies and services.

Therapies and Services

In a program, therapies and services are delivered pursuant to the plan of treatment. The intensity of delivery and frequency of therapies and services are dependent on the plan of care. They may be as frequently as 3 to 5 times per week.

In services, therapies, and other services are delivered by the individual disciplines pursuant to a physician's prescription.

Plan of Treatment

In a program, a plan of treatment is established and managed by the physiatrist or otherwise qualified rehabilitation physician and interdisciplinary team which outlines the patient's anticipated goals, type, amount, frequency, and duration of services. It is reviewed and revised by the team at regular intervals. Also, it is revised if there are other changes in the patient's condition.

In services, each discipline establishes its own plan of treatment which is reviewed by a physician at regular intervals. The services are managed by the individual disciplines under a physician's prescription.

6. Day Rehabilitation Programs

The day program is for people who still have persistent medical, rehabilitation, and rehabilitation nursing needs and who can benefit from an intensive rehabilitation therapy program. It provides an option for people who have families or others who can manage their night time medical and nursing needs.

A comprehensive medical day rehabilitation program provides evaluations, medical management, and supervision by a physiatrist or otherwise qualified rehabilitation physician, rehabilitation nursing services, and all rehabilitation therapies. The program is delivered by an interdisciplinary team of physicians, nurses and therapists pursuant to a plan of treatment. The patient usually arrives in the morning, spends all or part of the day in prescribed therapies, receives all the treatment and tests required and returns home.

A patient may be referred to a day rehabilitation program directly or from a less or more intense program.

- **Where Does This Occur?**

  Often, day rehabilitation programs are located in or are part of the outpatient department of a rehabilitation hospital, acute care hospital with a rehabilitation unit, or freestanding, comprehensive outpatient rehabilitation facility.

- **Components**

  Medical and Nursing Services

  Close, active medical management and supervision is provided by a physiatrist or otherwise qualified rehabilitation physician. Rehabilitation nursing including skilled medical nursing is also provided.

  Therapies and Services

  An intense level of coordinated therapies and services are provided 4 to 6 hours per day.

  Plan of Treatment

  A plan of treatment is established and managed by the physiatrist or otherwise qualified rehabilitation physician and the interdisciplinary team. It outlines the patient's anticipated goals, type, amount, frequency, and duration of services. It is developed in consultation with the physician and other members of the interdisciplinary team. It is reviewed by the team at least monthly and revised as necessary. Also, it is revised if there are other changes in the patient's condition.

7. Outpatient Rehabilitation Programs

Comprehensive outpatient medical rehabilitation programs also are available. An outpatient rehabilitation program is for people who are medically stable, require a physiatrist's or otherwise qualified rehabilitation physician's attention only periodically, but have not realized the goals of their rehabilitation plan. The program provides comprehensive rehabilitation services which are delivered under a plan of treatment. A plan of treatment may require that all services be delivered to the patient or only a few specific services. Individuals are transported to and from outpatient centers from their home or another residential setting. These programs may be focused on a specific diagnosis.

- **Where Does This Occur?**

  Typically, these programs are operated by freestanding, comprehensive outpatient rehabilitation facilities (CORFs), outpatient departments of rehabilitation or general acute care hospitals, or other organized outpatient rehabilitation facilities.

- **Components**

  Medical and Nursing Services

  The physiatrist or otherwise qualified rehabilitation physician evaluates the patient, establishes and manages the plan of treatment, and reviews and evaluates it and the patient at least every other month. The physician sees the person as needed but not less than every other month.

  Rehabilitation nursing may be provided to monitor stability and provide education for the patient, family, and/or others.

  Therapies and Services

  Therapies and services are delivered pursuant to the plan of treatment. The intensity of delivery and frequency are dependent on the plan of care. They may be as frequent as 3 to 4 times per week or less.

  Plan of Treatment

  A plan of treatment is established and managed by the physiatrist or otherwise qualified rehabilitation physician and interdisciplinary team. It outlines the patient's anticipated goals, type, amount, frequency, and duration of services. It is reviewed and revised by the team at least monthly. Also, it is revised if there are other changes in the patient's condition.

8. Outpatient Rehabilitation Services

Outpatient medical rehabilitation services may also be provided. They may be provided at the end of an overall treatment program or the patient may be referred directly from the community. Typically, there must be a physician prescription, however, some states allow certain therapists to provide a prescription for services. Outpatient medical rehabilitation services may be provided to people who are medically stable, require a physician's attention only periodically, but have certain residual deficits in some functional area. Services are provided by individual disciplines, and are delivered with plans of treatment developed by each separate discipline. Individuals may be transferred to and from the outpatient service area from their home or other residential settings.

- **Where Does This occur?**

  Most are operated by rehabilitation agencies, individual practitioners, outpatient rehabilitation facilities, and the outpatient departments of hospitals.

- **Components**

  Medical and Nursing Services

  A physician makes the referral for the needed rehabilitation services and gives a prescription for them. The physician sees the person as needed but on at least a monthly basis. The patient may be severely or slightly impaired. Rehabilitation nursing services are generally not provided.

  Therapies and Services

  Each discipline delivers its own services. One or more types of services may be delivered as frequently as 2 to 5 times per week depending upon the physicians' prescription. There is no formal coordination among the various disciplines delivering services.

  Plan of Treatment

  The physician or other professional, depending upon the state, establishes and manages the plan of treatment regarding goals, type, amount, and duration of services for each discipline but not in a coordinated manner.

9. Residential Rehabilitation Programs

People in a residential treatment program are medically stable but they may be prone to more complications than the general public. An extensive program of coordinated therapies and services is provided. They may be self-referred or referred by insurance companies, discharge planners, case managers, families, or rehabilitation hospitals or units. Such programs may focus on a specific disability such as pain, arthritis, head injury, or spinal cord injury.

Residential programs focus on returning the client to the community and living independently generally over a period of 6 to 18 months.

Patients in these programs are referred to as "clients" in order to focus on the reintegration aspect of this part of medical rehabilitation.

- **Where Does This Occur?**

  These programs are provided in or by transitional living centers, community reentry programs, or independent living centers.

- **Components**

  Medical and Nursing Services

  The program includes the availability of periodic, continued medical supervision and evaluation. General nursing services are available as needed.

  Therapies and Services

  Coordinated therapies and services are provided approximately 5 to 6 hours per day.

  Plan of Treatment

  A plan of treatment is established and managed by the interdisciplinary rehabilitation team which outlines the client's anticipated goals, type, amount, frequency, and duration of services. It is reviewed and revised by the team once a month. A member of the team is the designated program manager.

10. Vocational/Educational Rehabilitation Programs

Vocational rehabilitation and educational programs are outpatient programs. Medical rehabilitation is not the primary focus. The focus is on getting the person into or back into the work force or, depending on age and development, into school with an appropriate individual education plan, or back to an active, meaningful retirement. Clients may be referred from other rehabilitation programs, state vocational rehabilitation agencies, insurance companies, state workers compensation programs, and other services. Clients may begin participating in a vocational/educational program at any time in their recovery.

Only periodic medical checkups are provided, however, clients may require a greater amount of medical and personal support services than persons without disabilities.

Vocational programs provide coordinated, integrated programs of vocational assessment, evaluation, training, adjustment counseling, and placement. They also may include labor market analysis and vocational consultation. Limited medical rehabilitation services may also be provided.

Vocational rehabilitation and educational programs are transitional programs which seek to move people back to work, back to school, or back to retirement activities through a series of phased programs. They may or may not be associated with a residential or medical rehabilitation program.

- **Where Does This Occur?**

  These programs are usually found in vocational rehabilitation centers, special education programs, in public or private schools, vocational schools, residential programs, developmental centers, hospitals, or outpatient rehabilitation facilities with work evaluation, vocational evaluation, work hardening, or educational programs.

- **Components**

  Medical and Nursing Services

  Medical or nursing services are not generally provided or required.

  Therapies and Services

  Vocational/educational services and other therapies and services are provided from 1 to 40 hours per week, depending on the patient's functional status and ability to tolerate vocational/educational services.

  Plan of Treatment

  An assessment and a plan of treatment is established and managed by a rehabilitation counselor in consultation with other members of an interdisciplinary team.

VII. SUMMARY

This monograph has attempted to review the medical rehabilitation industry as it exists currently. Medical rehabilitation is a relatively young entrant in the health care industry but a growing one as the need for it and its benefits are recognized. Rehabilitation providers are diverse and cover the spectrum of care needed by rehabilitation patients.

Rehabilitation patients have diverse needs which must be addressed on a highly individual basis to achieve maximum functional ability. The rehabilitation industry will continue to meet these needs through growth, diversity, and ingenuity.

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A. DEFINITIONS OF REHABILITATION SERVICES INCLUDED IN COMPREHENSIVE MEDICAL REHABILITATION PROGRAMS

A. Medical Services

1. General Qualifications

Medical services are delivered by a physician who has the following qualifications:

a. A physiatrist: A physician specializing in physical medicine and rehabilitation certified by the American Board of Physical Medicine and Rehabilitation; or

b. A physician licensed under state law to practice medicine or surgery who has had a one-year hospital internship and at least two years specialized training and/or experience in rehabilitation and, in order to direct a rehabilitation program, at least two years of documented training or experience in the medical management of patients requiring rehabilitation services and an interdisciplinary team approach.

2. The Physician's Role

Physicians involved in comprehensive medical rehabilitation programs perform several roles. They provide the medical management and supervision for the rehabilitation program of the patient, identify the medical and functional problems after performing and documenting a complete history, physical examination and evaluation; and confirm the diagnosis and treat the consequences of this diagnosis while the patient is under his/her care. The rehabilitation physician decides the functional goals for the patient utilizing information from allied health professionals and oversees the interdisciplinary team as a primary program manager. The physician is familiar with the prognosis and rehabilitation potential for treatment and defines the needed interventions. The rehabilitation physician is responsible for ending treatment when rehabilitation potential has been reached.

B. Rehabilitation Nursing Services

Rehabilitation nursing involves special knowledge and clinical skills that are directed at the impact of disability upon individuals and their families and friends. Such knowledge and skills emphasize the magnitude of disruption to physical, social, emotional, economic, and vocational status.

Rehabilitation nursing services are designed to prevent complications of physical disability, the restoration of optimal functioning, and adaptation to an altered life style through the use of the nursing process, i.e., assessment, planning, intervention, and evaluation. Rehabilitation nurses carry out what has been learned in therapies, bowel and bladder training and management, and includes nursing for medical problems such as skin breakdown. Rehabilitation nursing services reduce the stigma of disability and facilitate coping mechanisms to help people reestablish and maintain a sense of control over their life. Rehabilitation nursing is committed to the prevention of disabilities and chronic illnesses.

C. Therapies and Other Services

1. Cognitive Therapy

Cognitive retraining services are individualized instructional services developed from an assessment and behavioral observation. Instructional activities are introduced in a systematic fashion utilizing available skills to rebuild intellectual processes including, but not limited to, concentration, perception, and problem-solving ability.

2. Durable Medical Equipment and Supplies

Durable medical equipment is equipment which (1) can withstand repeated use, (2) is primarily and customarily used to service a medical purpose, (3) generally is not useful to a person in the absence of illness or injury, and (4) is appropriate for use in the home. An item is considered "durable" if it can withstand repeated use, i.e., the type of item which could normally be rented. Medical supplies of an expendable nature, such as incontinent pads, catheters, and ace bandages, are not considered "durable" within the meaning of the definition.

"Medical equipment" is equipment which is primarily and frequently used for medical purposes and/or may be useful to persons with impairments. It includes, but is not limited to, respirators, intermittent positive pressure breathing machines, oxygen tents, hospital beds, and wheelchairs, etc.

Medically necessary equipment also includes equipment that is often specifically designed and fabricated for one individual to limit orthopedic deformities, replace and/or assist communicative function, prevent or correct skin or pressure problems, increase safety in individuals with seizures, relieve motor function limitations, and for positioning to allow swallowing.

3. **Educational Services**

Educational services are usually designed to enhance the educational functioning of the client. Depending on the client population served, rehabilitation facilities may offer remedial reading and mathematics, business, English, and mathematics, and assistance in acquiring the skills to obtain a high school equivalency diploma. Facilities providing services to mentally retarded or developmentally disabled persons may focus on functional academics that include menu and sign reading, counting money, and making change, etc. The educational program is usually offered with vocational training and may include tutoring for longer term patients.

4. **Nutrition**

Nutrition is the science of food and its effect on the body. It is concerned with the nutrients in food, their use in body chemistry and, in the final analysis, the relationship between diet and health. Dietitians provide nutritional counseling to individuals and groups, set up and supervise food service systems for institutions such as hospitals and schools, promote sound eating habits through education and research, and prescribe special diets.

5. **Occupational Therapy**

Occupational therapy services provide for goal-directed, purposeful activity to aid in the development of adaptive skills and performance capacities by individuals of all ages who have physical disabilities and related psychological impairment(s). Such therapy is designed to maximize independence, prevent further disability, and maintain health.

Occupational therapy services include meaningful activities to improve skills used in activities of daily living.

Treatment goals are achieved through the use of the following: task-oriented activities (including the simulation of actual practice of work self-care, leisure, social skills and their components, as well as the use of creative media, games, computers, and other equipment); prevocational/vocational activities; sensorimotor activities; and patient/family education and counseling. Occupational therapy treatment goals are also met through design, fabrication, and application of orthotic devices, as appropriate; guidance in the use of adaptive equipment and prosthetic devices; adaptation of the physical and social environment and the use of therapeutic milieum; joint protection/body mechanics; and positioning.

6. **Pastoral Counseling Services**

The term "pastoral counseling" refers to a process in which a pastoral counselor utilizes insights and principles derived from the disciplines of theology and the behavioral sciences in working with individuals, couples, families, groups, and social systems toward the achievement of wholeness and health.

The term "pastoral counselor" refers to a minister who practices pastoral counseling at an advanced level which integrates religious resources with insights from the behavioral sciences.

7. **Physical Therapy**

Physical therapy services provide identification, prevention, remediation, and rehabilitation of acute prolonged physical dysfunction or pain, with emphasis on movement dysfunction. Such therapy encompasses examination and analysis of patients and the therapeutic application of physical and chemical agents, exercise, and other procedures to maximize functional independence.

Physical therapy services include, but need not be limited to:

- Initial evaluation and assessment;
- Determining and developing treatment goals and plans in accordance with the diagnosis and prognosis;
- Therapeutic interventions that focus on posture, locomotion, strength, endurance, cardiopulmonary function, balance, coordination, joint mobility, flexibility, pain, and functional abilities in daily living skills;
- Modalities that include, but need not be limited to, heat, cold, light, air, water, sound, electricity, massage, mobilization, broncopulmonary

hygiene, and therapeutic exercise with or without assistive devices;

- Assessment and training in locomotion, including, as appropriate, the use of orthotic, prosthetic, or assistive devices; and

- Patient and family education, as appropriate.

8. **Prosthetics and Orthotics**

Prosthetic and orthotic services are provided by specialists qualified to manage the prosthetic or orthotic needs of persons with disabilities by performing examinations, participating in prescribing specialized equipment, designing and fitting such equipment, and following up to see that the equipment fits and functions properly.

Monitoring activities address patient satisfaction with the orthotic or prosthetic devices relative to fit and functioning.

9. **Psychological Services**

Psychological services focus on the patient's and family's adaptation to the patient's disability and on the assessment of psychological deficits associated with the physical disability.

Psychological services include, but need not be limited to:

- Assessment, including psychological, vocational, and neuropsychological functioning; and

- Interventions, including individual and group psychotherapy, family consultation and therapy, and the design of such specialized psychological intervention programs as behavior modification, behavioral treatment regimens for patients with chronic pain, and biofeedback, relaxation procedures, and cognitive retraining.

10. **Rehabilitation Counseling Services**

Rehabilitation counseling helps disabled individuals to lead as normal a life as possible. Rehabilitation counseling services require the rehabilitation counselors to learn about their client by talking with him or her, reading school or work reports, conferring with medical personnel, and talking with family members to determine the exact nature of the disability and its relationship to living independently. If the disability occurred after the person had begun his or her work life, counseling services entail exploring and evaluating training and career options, evaluating the potential for returning to competitive employment, and using this information to develop a rehabilitation program.

A rehabilitation program may begin with specialized training to help make a disabled person more independent generally. The amount of time spent counseling each client varies with the severity of the disabled person's problems, as well as with the size of the counselor's caseload.

11. Rehabilitation Engineering

The term "rehabilitation engineering" means the systematic application of technologies, engineering methodologies, or scientific principle to meet the needs of and address the barriers confronted by individuals with handicaps in areas which include education, rehabilitation, employment, transportation, independent living, and recreation.

Rehabilitation engineering uses engineering principles to solve medical and health-related problems. This includes design and development of medical instruments and devices, adapting computers to medical science, and designing and building systems to modernize laboratory, hospital, and clinical procedures.

12. Respiratory Therapy

Respiratory therapy services are prescribed by a physician and provide for the assessment, diagnostic evaluation, treatment, management, and monitoring of patients with deficiencies and abnormalities of cardiopulmonary function. Respiratory therapy services include, but are not limited to:

1. The therapeutic use and monitoring of medical gases (especially oxygen), bland and pharmacologically active mists and aerosols, and such equipment as resuscitators and ventilators;
2. Bronchial hygiene therapy, including deep breathing and coughing exercises, IPPB, postural drainage, chest percussion and vibration, and nasotracheal suctioning;

3. Diagnostic tests for evaluation by a physician, e.g., pulmonary function tests, spirometry, and blood gas analyses;

4. Pulmonary rehabilitation techniques, which includes: (a) exercise conditioning; (b) breathing retraining; and (c) patient education regarding the management of the patient's respiratory problems; and

5. Periodic assessment and monitoring of the acute and chronically ill patients for indications for, and the effectiveness of, respiratory therapy services.

   Such services are performed by respiratory therapists or technicians, physical therapists, nurses, and other qualified personnel.

13. **Social Work Services**

Depending on their qualifications, social workers evaluate and treat problems in psycho-social functioning or refer clients to other qualified resources for assistance. Treatment interventions commonly include, but are not limited to, psychosocial evaluation; counseling of individuals, families, and groups; advocacy; referral to community resources; and facilitation of organizational change to meet social needs. Social workers also provide professional services for the diagnosis, treatment, and prevention of mental and emotional disorders in individuals, families, and groups with the goal of restoring, maintaining, or enhancing social functioning. Treatment interventions include counseling. Individual state practice laws may vary.

14. **Speech/Language Pathology and Audiology Services**

Speech-language pathology and audiology services provide for a continuum of services, including prevention, identification, diagnosis, consultation, and the treatment of patients regarding speech, language, oral and pharyngeal sensorimotor function, hearing, balance, swallowing and cognitive communicative process/functions.

Services include:

- Screening to determine the presence or absence of a communicative disorder;

- Evaluating and diagnosing speech, language, and oral and pharyngeal sensorimotor competencies, and evaluating and diagnosing auditory and vestibular competencies.
- Planning, directing, and conducting habilitative, rehabilitative, and counseling programs to treat disorders of verbal and written language, voice, articulation, fluency, interactive communication, chewing, swallowing, auditory and/or visual processing and memory and cognition/communication; and assisted, and/or augmentative communication treatment and devices; and
- Planning, directing, and conducting aural habilitation and rehabilitation programs by the audiologist.
- Provide training in the use of voice replacement instruments.

15. Therapeutic Recreation

Recreation and other leisure-time activity services provide for the development, maintenance, and expression of an appropriate leisure/social lifestyle for individuals with physical, mental, emotional, or social limitations.

Therapeutic recreation services provide, but need not be limited to:

- An assessment of the patient's leisure, social, and recreational abilities, deficiencies, interests, barriers, life experiences, needs, and potential;
- Treatment services designed to improve social, emotional, cognitive, and physical functional behaviors as necessary prerequisites to future leisure/social involvement; and
- Leisure education designed to help the patient acquire the knowledge, skills, and attitudes needed for independent leisure/social involvement, adjustment in the community, decision-making ability, and appropriate use of free time.

16. Transitional Living

Transitional living services are alternatives to long-term institutional placement of patients such as persons with head injuries requiring a 24-hour treatment and training program. The focus of transitional living services is on vocational skills, community reintegration, social behavior, and daily living skills.

17. Vocational Rehabilitation Services

Vocational rehabilitation services provide for assessment and evaluation through testing, counseling, and other related activities of the patient's need for services and training designed to enable him to return to productive activity.

Vocational rehabilitation services are comprehensive and include, at a minimum:

- Prevocational evaluation, including evaluation of physical and intellectual capacity; interests and attitudes; emotional and social adjustments; work skills and capabilities; vocational potential and objectives;
- Prevocational training;
- Vocational rehabilitation plan;
- Work assimilation and adjustment;
- Vocational training;
- Transitional services; and
- Placement services.

D. Interdisciplinary Team

The interdisciplinary team refers to activities performed towards a common goal by individuals from different disciplines. Team members not only require the skills of their own disciplines, but also the added responsibility of the group effort on behalf of the activity or client involved. This effort requires the skills necessary for effective group interaction and the knowledge of how to transfer integrated group activities into a result which is greater than the simple sum of the activities of each individual discipline.

Team members seek to accomplish an outcome which is greater than that of each functioning separately. To produce this outcome, they require skills which go beyond those of their own disciplines. Since each shares the responsibility for the group activity, each needs to have knowledge regarding the general principles of the others' approach and sufficient technical awareness of the activities of the others to question whether the other members have sufficiently completed their own areas of responsibility.

The team also is responsible for managing each individual case and, in doing so, deciding when a patient/client should move to another program level. The physician is the team leader, however, another member of the team may be the case coordinator responsible for, among other things, contact with any outside payment sources.

E. Case Management

Case management is defined as a coordinated process which is part of the patient's individual plan of care. It aims to ensure that the patient's health and health-related needs are identified, properly assessed and appropriately met. These activities involve following the patient through the hospital stay and arranging for after care and services. Medical intervention of disease processes or injuries involves choices about a series of options. The role of the case manager is to evaluate the appropriateness of these options and to select alternatives. This selection involves the family, attending medical staff and rehabilitation providers, and the employer. The functions the case manager performs are case finding and screening, assessment, developing the plan of care, implementing the plan, monitoring the case, and post-acute care management.

An important key to the success of health care management is early intervention by the team. The case manager's emphasis is on rapid movement through the acute level of care into specialized care as soon as the patient's condition is stabilized. The emphasis relies on an early referral mechanism which is marketed and established by the health care management team. This early intervention and management can contribute to cost savings.

F. Other Services

1. Dental
2. Diagnostic (e.g., laboratory, radiology)
3. Pharmacy
4. Pediatric
5. Rehabilitation surgery

B. WORLD HEALTH ORGANIZATION DEFINITIONS

The World Health Organization (WHO) defines the terms "disability," "impairment," and "handicap" as follows:

> disability - in the context of health experiences, a disability is any restriction or lack of, (resulting from impairment) of ability to perform an activity in a manner or range considered normal for human beings.
>
> impairment - in the context of health experiences, any loss or abnormalities of psychological, physiological, or anatomical structure or function.
>
> handicap - in the context of health experiences, a handicap is a disadvantage for a given individual resulting from impairment, which limits or prevents the fulfillment of a role that is normal (depending on age, sex, social and cultural factors) for the individual.

Functional Assessment in Rehabilitation Medicine, Granger & Gresham, 1984, Williams & Wilkins, Baltimore/London.

C. DEFINITIONS OF MEDICAL AND COMPREHENSIVE REHABILITATION

A. Medical Rehabilitation

For purposes of this monograph, medical rehabilitation refers to the evaluation, diagnosis, treatment, and procedures which seek to minimize physical and cognitive impairments, prevent institutionalization and reinstitutionalization, maximize functional ability, and restore lost functional capacity, thereby reducing the impact of a disability on the quality and productivity of the patient's life.

B. Comprehensive Rehabilitation

For purposes of this monograph, comprehensive rehabilitation means programs encompassing the organized, coordinated, interactive, goal-directed, integration of rehabilitation services under the direction of an interdisciplinary team.

This team is responsible for evaluating the patient, establishing a plan of treatment, assessing the patient's progress within specific time frames, achieving the rehabilitation program's objectives, providing additional clinical care when indicated, and regularly measuring the patient's progress.

D. SUMMARIES OF PATIENT GROUPS & REHABILITATION PROGRAMS & SERVICES

1. PATIENT GROUPINGS: SUMMARY

	1	2
Introduction	These patients are the most severely ill patients immediately post trauma or disease. Their rehabilitation potential is most uncertain at this stage of recovery. Good rehabilitation techniques during this period can improve potential for recovery as well as prevent secondary complications.	These patients may still have serious medical problems, however health status is sufficiently resolved to shift the primary focus of care to rehabilitation. There is a reasonable expectation that rehabilitation potential exists and that a comprehensive rehabilitation program will improve functional status.
Health Status	Group 1 patients have severe abnormalities of one or more body systems secondary to disease or trauma. The extent of their pathology tends to change signficantly over hours or days. They usually demonstrate change towards improved medical/clinical status, but often slow progression in their pathology. They are highly vulnerable to significant secondary involvement of additional body systems and to major complications of already imvolved systems. These complications are likely to produce changes which occur rapidly, sometimes within minutes. These patients remain highly vulnerable to death or permanent system compromise unless homeostasis (a physically steady state) is developed and maintained through appropriate medical and nursing involvement.	Group 2 patients have significant abnormalities of one or more body systems secondary to disease or trauma. The extent of their pathology tends to change significantly over days. They almost always demonstrate change towards improved status. They may develop secondary involvement of additional body systems or complications of already involved body systems. Some of these complications may produce rapid changes (within minutes) but others may develop over hours or days. These patients remain significantly vulnerable to death or permanent system abnormality unless homeostasis is developed and maintained through appropriate medical and nursing involvement. While health status continues to be abnormal, the patient now needs rehabilitation to enhance functional status. The patient's medical problems may also require daily physician management by a general or attending physician in addition to the physiatrist or otherwise qualified rehabilitation physician.
Functional Status	The patient is dependent in multiple functional areas. Total physical care usually is required by virtue of the person's physical disability and/or acute medical condition. Eventual residual physical impairment is unknown at this time.	The patient is dependent in multiple functional areas requiring coordinated efforts of multiple rehabilitation specialists to learn or relearn how to meet daily needs. The patient is expected to be able to tolerate, participate in and benefit from sufficiently intense therapies and services and expected to show functional improvements in relatively short periods of time generally at least every two weeks. However, from time to time, medical problems may temporarily interfere with the patient's ability to tolerate and benefit from therapies. The patient continues to improve his or her status toward established goals. The person's dependency prohibits living at home. The risk of increased dependency due to receiving less intense care exists.
Social Status	The patient's family or others are generally very involved emotionally during the critical phase. Their focus is typcially on the patient's survival, with little comprehension of the potential long-term implications.	The patient's family or others, even if they are present and willing supporters, cannot meet the patient's current physical and psychosocial needs. They will require education to help the patient in these areas. The presence, desire and ability of the family and others to help the patient and be educated as to his/her needs is important.
Vocational/ Educational Status	The patient may have potential to return to work, an educational setting, or, if retired, to an active, meaningful retirement, but this potential cannot be completely evaluated at this time.	The patient may have potential to return to work, an educational setting, or, if retired, to an active, meaningful retirement, but this potential cannot be completely evaluated at this time.

	3	4
Introduction	The patient is more medically stable but continues to have medical complications related to the impairment. The underlying medical condition is still serious and requires continued medical involvement.	These patients are moderately ill, having stabilized or markedly slowed in their recovery from trauma or disease. Their physical impairments and/or disabilities may benefit from selected rehabilitation services to prevent complication and improve their limited functions. This group includes long-term chronic care patients. Rehabilitation services with help, preserve existing functional ability, help prevent complications and restore function.
Health Status	Group 3 patients have significant abnormalities of one or more body systems secondary to disease and trauma. The extent of their pathology remains essentially stable. They are unlikely to develop secondary involvement of additional systems or complication involving already involved systems. These patients remain somewhat vulnerable to permanent system compromise unless homeostasis is maintained through appropriate medical and nursing involvement.	Group 4 patients have residual abnormalities of one or more body systems secondary to disease or trauma. The extent of their pathology remains essentially stable. They are unlikely to develop secondary involvement of additional systems or complications of already involved systems. These patients remain significantly vulnerable to permanent system compromise unless homeostasis is maintained through appropriate medical and nursing involvement.
Functional Status	The patient is dependent in multiple areas. He or she requires the coordinated efforts of multiple rehabilitation specialists to learn or relearn methods to meet daily needs. The patient is expected to be able to participate in and benefit from a number of coordinated therapies and services and is expected to show functional improvement generally more than every two weeks. The patient continues to progress in improving his or her functional status toward established goals. The patient's dependency prohibits living at home at this time. The rate of change and improvement is slower than for a patient in group 1 or 2.	The patient may be dependent in several areas. He or she requires some rehabilitation services to learn or relearn methods to meet daily needs; is expected to be able to participate in and benefit from a limited number of therapies and services and is expected to show improvement or prevent deterioration of current functional levels. The patient's dependency prohibits living at home. Hence the rate of change and improvement is slower than for a patient in a group 1, 2 or 3 program. A more intense program would not increase the patient's rate of change.
Social Status	The presence, desire and ability of the family and others to help the person and be educated as to his/her needs is important. At this point the patient's family or others are willing supporters, but cannot meet his/her current physical and psychosocial needs and require education to help the patient in these areas.	The presence, desire and ability of the family and/or others to help the patient and be educated as to his/her needs is important. At this point the patient's family and/or others are willing supporters, but cannot meet his/her current needs and will require education to help the patient in these areas.
Vocational/ Educational Status	The patient may have potential to return to work, an educational setting, or, if retired, to an active, meaningful retirement and may have a prevocational/educational assessment at this time.	The patient may have potential to return to work, an educational setting, or, if retired, to an active, meaningful retirement, but it is unlikely.

	5	6
Introduction	These patients are moderately ill having stabilized or markedly slowed in their recovery from trauma or disease. Their physical impairments and/or disabilities may benefit from selected rehabilitation services to prevent complications and improve their limited functions. The family or others can care for the majority of their nursing needs and personal care. Group 5 patients may need rehabilitation services at home because of their lack of ability to travel. Many of these patients are served on an outpatient basis at home with family or others' support and certain needed services are available. Rehabilitation services will help restore more independent function, preserve existing functional abilities, and/or help prevent complications.	The patient is medically stable enough not to require inpatient care, but requires regular physician attention to monitor and treat the consequences of the impairment(s) to the organ systems and to prevent complications of the primary or secondary diagnoses. The patient continues to require rehabilitation nursing services to monitor, education, and pursue new skills in the rehabilitation program. From a social and functional standpoint there are several subsets to this group. These are based on the availability of adequate family, social or community services to help the patient live outside the inpatient setting. These patients also have differences in their functional status and different levels of ability in various aspects of their functional status.
Health Status	Group 5 patients have residual abnormalities of one or more body systems and severe functional deficits. The extent of their pathology remains essentially stable. They are unlikely to develop secondary involvement of additional systems or complications of already involved systems. They remain vulnerable to system compromise unless homeostasis is maintained through appropriate attention to nursing needs and therapeutic intervention.	Group 6 patients have persistent abnormalities of one or more body systems secondary to disease or trauma. Their pathology remains stable and they are generally unlikely to have secondary involvement or complications if homeostasis is maintained through appropriate medical, nursing and attendant care as indicated. Their pathology remains essentially stable and they are unlikely to develop additional complications. They may continue to have needs which are met by appropriately trained family or others in their residential setting.
Functional Status	The patient may be dependent in several areas. The patient requires some rehabilitation services to learn or relearn how to meet daily needs, is expected to be able to participate in and benefit from a limited number of therapies and services. From the therapies and services, the patient is expected to show functional improvement, avoid deterioration of current functional levels and/or prevent complications.	Subgroup A. The patient is dependent in several areas and is expected to tolerate, participate and benefit from intense, coordinated multiple therapies and services and is expected to show improvements against specified goals in reasonable periods of time. He or she requires a coordinated rehabilitation program to learn or relearn how to meet daily needs. Subgroup B. The patient's total functional ability is not at the level anticipated for his or her rehabilitation goals and can improve with prescribed rehabilitation services.
Social Status	The family or others are able to meet the patient's daily needs at home, provided that other professional services are available.	Subgroup A. Patients need external, knowledgeable support in one or more areas with which a patient may move toward more independent functioning. With this support, the patient may move into transitional, residential or independent living. This support may be provided by an appropriately trained family, community support, transitional living center or other supportive unit or services. Subgroup B. The patient may be able to live independently with or without supportive services at home.
Vocational/ Educational Status	The patient may have potential to return to work, an educational setting, or, if retired, to an active, meaningful retirement. This can be determined by periodic vocational, educational, recreational evaluations with a rehabilitation plan developed subsequent to the evaluations.	The patient may need a prevocational, educational or recreational assessment, of his/her potential to return to a work setting, school or retirement activities. Vocational and educational status prior to the disabling incident also influences whether such assessment(s) are needed. The patient may be able to particpate in a vocational, educational or recreational plan, testing and possibly training or education.

	7	8
Introduction	The patient's medical condition is stable but he or she may be more prone to medical complications than the general population. Routine evaluations are needed to assure that functional status is maintained and to assess the requirement for continued therapy. The patient does not require regular nursing services. A personal care assistant may be needed to help with activities of daily living. Patients in this group may not require complete assistance in mobility or activities of daily living, but may lack mental, cognitive, behavioral and communicative ability and cannot maintain himself or herself in a manner that assures physical safety alone.	The person is medically stable, not at risk and may have a good recovery. The person may require only routine evaluation to assure that functional status is maintained and to assess the need for therapy. The person is responsible for identifying his/her own medical problems requiring help and for scheduling appointments.
Health Status	Group 7 patients continue to have abnormalities of one or more body systems due to disease or trauma. Their pathology remains stable and they are generally unlikely to have secondary involvement or complications if homeostasis is maintained through appropriate medical, nursing and personal aides' involvement, if needed.	Group 8 patients may or may not still have medical impairments or one or more body systems due to disease or trauma. Pathology remains stable. The risk for secondary involvement and complications remains low as long as the patient follows any prescribed program of personal care.
Functional Status	The patient is dependent in significant functional areas. Psychosocial needs may outweigh medical needs. The person is expected to participate in and benefit from a coordinated program of services to reintegrate into the community.	The patient can perform at all functional activities within his or her capacity in spite of the impairments. This may include the use of a personal care attendant.
Social Status	Patients need knowledgeable, external emotional and cognitive support in one or more areas (physical, emotional, cognitive, transportation, housing) without which the patient may not be able to move toward more independent functioning, transitional, residential or independent living. This may be provided by an appropriately trained family, community support or transitional living center or other supportive unit based on availability and the patient's functional status.	The person is living independently, either on his or her own, with family, with others, or in an alternative living setting.
Vocational/ Educational Status	The person may participate in a vocational or educational assessment of the ability to return to work setting, school or retirement activities and programs involving, as needed, vocational training, work adjustment, placement services, recreation and education.	The person may have residual functional problems which interfere with vocational, educational, or retirement activities. The person can participate in vocational and/or educational programs, including assessment, a vocational plan, vocational training, work assimilation, work adjustment and placement services. The person may be employed in a work program specific to his or her needs while continuing to see a vocational rehabilitation counselor. The person can participate in education courses, or recreation courses to help achieve an active, meaningful retirement.

2. MEDICAL REHABILITATION PROGRAMS AND SERVICES: SUMMARY

1

Rehabilitation Components in Acute Care

Introduction

This program includes all those persons who survive transport to the hospital after an injury or illness and who are acutely ill and/or medically unstable.

The program has surgical and diagnostic capabilities for management of acute traumatic injury or illness, e.g., radiology, lab, and surgery. It includes a variety of medical specialties available for consultation and primary care, e.g., internal medicine, orthopedics, neurology, surgery, rehabilitation, and pulmonology. The primary emphasis in this program is on stabilizing the patient's medical/surgical needs and survival. Rehabilitation components are provided, for example, passive exercises, positioning and splinting to prevent contractures and complications, and speech/language pathology to assist in swallowing.

2

Rehabilitation Hospitals and Units

These comprehensive inpatient medical rehabilitation programs are for persons who are still medically fragile, have severe functional impairments, and need the support of a medical facility. They have potential for improving their functional abilities at regular intervals.

Such programs provide close medical supervision by a physiatrist or otherwise qualified rehabilitation physician. Such physicians are available on a 24-hour basis. Additionally, the program provides 24-hour availability of registered nurses with specialized training and experience in rehabilitation. A program provides at least 8.5 hours of rehabilitation nursing and therapies such as physical therapy, occupational therapy, speech, and psychosocial services daily.

The program includes an interdisciplinary team consisting of the physician, rehabilitation nurse and therapists. The interdisciplinary team provides the patient's program through a coordinated program of care that is documented. Team conferences are held at least every two weeks to assess the patient's progress, problems impeding progress and assessing the initial rehabilitation goals.

A program of this nature provides preadmission screening for a patient to determine if a patient is likely to benefit significantly from an intensive, comprehensive rehabilitation program. The preadmission screening may take place in the rehabilitation facility or the facility in which the patient is currently residing.

After screening, the program provides an extensive professional review of the patient's condition by the physiatrist or otherwise qualified physician and the interdisciplinary rehabilitation team. Such assessments usually require between 3 to 10 calendar days, but on occasion may require more. Even if a patient received therapies prior to admission, an initial assessment period is reasonable and necessary.

This type of program is necessary for a patient who requires a more coordinated, intensive program of multiple services than generally found in other rehabilitation programs. A patient who has one or more conditions requiring intense, interdisciplinary rehabilitation care or who has medical complications in addition to the primary condition so that the continuing availability of a physician is required to insure safety and treatment, requires this type of rehabilitation program.

The goals of the program assume a reasonable expectation of improvement for the patient measured against his or her admitting condition. The program sets realistic goals for patients in view of their status. It continues until further progress towards the established goals are achieved and the patient goes home or progress continues

		at such a slow rate that the patient can be served better in another facility. It is at this time and in this program that major decisions about the patient's future placement are made. In making this determination the team looks at the degree of improvement that has occurred and the type of program required to achieve further improvement. The program may include occasional home visits and trips into the community as part of the therapeutic program to determine whether the patient should continue to stay in the program. Such visits and trips are used to test the patient's ability to function outside the institutional setting and to assist in discharge planning for the patient. Discharge planning is a process which involves the family, the patient, the treatment team, and may include the payor.
Where Does This Occur?	Short-term general acute care hospitals, general acute care hospitals, general medical/surgical wards, trauma centers and intensive care units may offer these components. Many communities have designated trauma units designed to provide early critical care to trauma victims.	These comprehensive inpatient medical rehabilitation programs usually are found in freestanding rehabilitation hospitals or rehabilitation units of general acute care hospitals. These programs are usually accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) for comprehensive inpatient rehabilitation programs, the Joint Commission on Accreditation of Healthcare Organizations for rehabilitation, and/or the American Osteopathic Association. Currently, there are nine (9) skilled nursing facilities with CARF accreditation for inpatient rehabilitation programs. This is an exception, not the norm. Over 50 percent of them are for persons with head injuries.
Components: Medical and Nursing Services	At this acute level, care is provided by a multidisciplinary team of specialists which include physicians, critical care nurses, respiratory therapists, dieticians, pharmacists, and sometimes rehabilitation clinical professionals. A multidisciplinary, critical care team including rehabilitation professionals is essential to manage the patient's unstable condition. Critical care nurses generally provide 10 to 16 hours of nursing care per day. Continuous physician management is achieved with a minimum of daily visits and frequent communication with nursing staff. This level of care requires a high level of nursing care including 24-hour medical and or surgical nursing. Physician involvement is continuous and is usually provided by a team of specialists.	Close, daily, on-site, active medical management and supervision by a physiatrist or otherwise qualified rehabilitation physician, and daily presence of this physician, is provided as well as 24-hour rehabilitation nursing in addition to skilled medical/surgical nursing. Other medical specialists are available as needed.
Therapies and Services	Rehabilitation therapies and services, such as occupational therapy, physical therapy, and speech/language pathology services are initiated to maximize the patient's potential for recovery. Therapy services may be provided consistent with the patient's tolerance. The major focus is to prevent or minimize secondary complications; however, rehabilitation services also have a positive effect on the speed of recovery.	Intensive, coordinated services and therapies are provided as outlined in the plan of treatment. A minimum of 8.5 hours per day for a minimum of five days a week of rehabilitation nursing, therapies, and services are delivered by an interdisciplinary team. CARF requires a minimum of 5.5 nursing hours per day; Medicare requires a minimum of 3 hours of specified therapies a day, five days a week.

Plan of Treatment	The plan of treatment is established and managed by the physician and acute care staff. The plan is revised frequently, as the patient's condition is very fragile, and may change on a daily or even hourly basis.	A plan of treatment is established and managed by the physiatrist or otherwise qualified rehabilitation physician and the interdisciplinary team. It outlines the person's anticipated goals, type, amount, frequency, and duration of services. It is reviewed by the team every two weeks and revised as necessary. It is also revised if there are other changes in the person's condition.

	3 **Atypical Nursing Homes**	4 **Typical Nursing Homes**
Introduction	These comprehensive inpatient medical rehabilitation programs are for people who are sick and disabled enough to require institutional support. These people have the potential for significant gains in functional improvement but improvement will occur at a rate slower than every two weeks. This program has similarities to inpatient hospital-based comprehensive rehabilitation programs but is less intense. It provides a rehabilitation evaluation at the time of referral to the rehabilitation facility, medical management by a physiatrist or otherwise qualified rehabilitation physician, and 24-hour rehabilitation nursing care and an interdisciplinary treatment team.	Many nursing homes currently provide only intermittent, individual rehabilitation services which focus on preventing deterioration of function or improving a patient's level of function, as opposed to providing a comprehensive program. They work with patients to restore function at a very slow rate. These patients have rehabilitation needs, but rehabilitation is not the primary focus. An evaluation at referral, medical management by a physician, and nursing care are required. Services may be delivered periodically as often as three times per week or as little as once a month. In some instances, services are not on a one-on-one basis, delivered by a therapist to one patient, but may consist of group sessions with a therapist and an aide working with a group of nursing home residents in an exercise course of other general activity that is not specific to each patient's condition.
Where Does This Occur?	This program is most typically found in a nursing facility that has a comprehensive inpatient rehabilitation program. This program may be delivered also in a rehabilitation hospital or unit when an appropriately organized nursing facility is not available.	These services are found in general nursing homes which do not have comprehensive rehabilitation programs. They are focused primarily on treating chronically ill patients with long-term medical and nursing needs.
Components: Medical and Nursing Services	A physiatrist or otherwise qualified rehabilitation physician provides the medical management of the patient and provides those services at least once a week; however, these services are available 24 hours per day. Rehabilitation nursing in addition to skilled medical/surgical nursing is provided 24 hours a day.	These patients require physician services and review once a month, 24-hour nursing care and 24-hour availability of a physician.
Therapies & Services	Coordinated therapies and services are provided as outlined in the plan of treatment. The total hours of rehabilitation nursing, therapies, and services delivered by an interdisciplinary team per day is at least five hours per day. More intensive therapy and services do not make this patient's rehabilitation happen faster.	Typically these programs include individual rehabilitation therapies and services only by physician's prescription as need dictates.
Plan of Treatment	A plan of treatment is established and managed by the physiatrist or otherwise qualified rehabilitation physician in consultation with other members of the interdisciplinary team. The plan includes the patient's anticipated goals, type, amount, frequency and duration of services, and is reviewed and revised by the team at least once a month. It is also revised if there are changes in the patient's condition.	A plan of treatment is established and managed by a physician outlining amount, frequency, and duration of services. It is reviewed monthly and revised as needed.

MEDICAL REHABILITATION OUTPATIENT PROGRAMS

	5 **Rehabilitation Programs and Services Delivered in the Home**	6 **Day Rehabilitation Programs**
Introduction	Home rehabilitation programs are also available. A home health program is for people who are relatively medically stable and require a physiatrist's or otherwise qualified rehabilitation physician's attention only periodically, but have not realized the goals of their rehabilitation plan. A physiatrist or otherwise qualified rehabilitation physician performs an evaluation in coordination with the interdisciplinary team, establishes a plan of treatment, and monitors medical stability. Home health rehabilitation programs are delivered in the patient's home because the patient has an impairment or medical condition that prevents him or her from going to an outpatient facility. In some instances when familiar surroundings enhance the therapy, home care may be appropriate. Both comprehensive medical rehabilitation programs and rehabilitation services may be delivered in the home. Generally, home programs deliver rehabilitation services, however, the nursing needs of the patient may dominate. Atypical home programs include a comprehensive medical rehabilitation program. These rehabilitation programs may not be as involved as a comprehensive medical outpatient rehabilitation program since, for example, all the equipment may not be brought into the home but they do provide for the patient's needs. Whether a home program or service is delivered will depend on local availability and the patient's needs for multiple services or an individual service.	The day program is for people who still have persistent medical, rehabilitation, and rehabilitation nursing needs and who can benefit from an intensive rehabilitation therapy program. It provides an option for people who have families or others who can manage their night time medical and nursing needs. A comprehensive medical day rehabilitation program provides evaluations, medical management, and supervision by a physiatrist or otherwise qualified rehabilitation physician, rehabilitation nursing services, and all rehabilitation therapies. The program is delivered by an interdisciplinary team of physicians, nurses and therapists pursuant to a plan of treatment. The patient usually arrives in the morning, spends all or part of the day in prescribed therapies, receives all the treatment and tests required and returns home. A patient may be referred to a day rehabilitation program directly or from a less or more intense program.
Where Does This Occur?	Typically, these programs are delivered primarily through home health agencies, hospital outpatient departments or outpatient rehabilitation facilities. Candidates for home programs may be referred from acute care hospitals, an inpatient rehabilitation, program 2 or program 3, or day rehabilitation programs. More often, home programs provide services. Emerging home rehabilitation programs provide a rehabilitation program.	Often, day rehabilitation programs are located in or are part of the outpatient department of a rehabilitation hospital, acute care hospital with a rehabilitation unit, or freestanding, comprehensive outpatient rehabilitation facility.
Components: Medical and Nursing Services	In a program, the physiatrist or otherwise qualified rehabilitation physician evaluates the patient, establishes and manages the plan of treatment, and reviews and evaluates it and the patient at least every other month. The physician sees the person as needed but not less than bimonthly. Rehabilitation nursing is provided to monitor stability and provide education for the patient and/or family/others.	Close, active medical management and supervision is provided by a physiatrist or otherwise qualified rehabilitation physician. Rehabilitation nursing including skilled medical nursing is also provided.

	When services are required, the physician evaluates and refers the patient for the needed nursing and therapies and services.	
Therapies & Services	In a program, therapies and services are delivered pursuant to the plan of treatment. The intensity of delivery and frequency of therapies and services are dependent on the plan of care. They may be as frequently as 3 to 5 times per week. In services, therapies, and other services are delivered by the individual disciplines pursuant to a physician's prescription.	An intense level of coordinated therapies and services are provided 4 to 6 hours per day.
Plan of Treatment	In a program, a plan of treatment is established and managed by the physiatrist or otherwise qualified rehabilitation physician and interdisciplinary team which outlines the patient's anticipated goals, type, amount, frequency, and duration of services. It is reviewed and revised by the team at regular intervals. Also, it is revised if there are other changes in the patient's condition. In services, each discipline establishes its own plan of treatment which is reviewed by a physician at regular intervals. The services are managed by the individual disciplines under a physician's prescription.	A plan of treatment is established and managed by the physiatrist or otherwise qualified rehabilitation physician and the interdisciplinary team. It outlines the patient's anticipated goals, type, amount, frequency, and duration of services. It is developed in consultation with the physician and other members of the interdisciplinary team. It is reviewed by the team at least monthly and revised as necessary. Also, it is revised if there are other changes in the patient's condition.

	7 **Outpatient Rehabilitation Programs**	8 **Outpatient Rehabilitation Services**
Introduction	Comprehensive outpatient medical rehabilitation programs also are available. An outpatient rehabilitation program is for people who are medically stable, require a physiatrist's or otherwise qualified rehabilitation physician's attention only periodically, but have not realized the goals of their rehabilitation plan. The program provides comprehensive rehabilitation services which are delivered under a plan of treatment. A plan of treatment may require that all services be delivered to the patient or only a few specific services. Individuals are transported to and from outpatient centers from their home or another residential setting. These programs may be focused on a specific diagnosis.	Outpatient medical rehabilitation services may also be provided. They may be provided at the end of an overall treatment program or the patient may be referred directly from the community. Typically, there must be a physician prescription, however, some states allow certain therapists to provide a prescription for services. Outpatient medical rehabilitation services may be provided to people who are medically stable, require a physician's attention only periodically, but have certain residual deficits in some functional area. Services are provided by individual disciplines, and are delivered with plans of treatment developed by each separate discipline. Individuals may be transferred to and from the outpatient service area from their home or other residential settings.
Where Does This Occur?	Typically, these programs are operated by freestanding, comprehensive outpatient rehabilitation facilities (CORFs), outpatient departments of rehabilitation or general acute care hospitals, or other organized outpatient rehabilitation facilities.	Most are operated by rehabilitation agencies, individual practitioners, outpatient rehabilitation facilities, and the outpatient departments of hospitals.
Components: Medical and Nursing Services	The physiatrist or otherwise qualified rehabilitation physician evaluates the patient, establishes and manages the plan of treatment, and reviews and evaluates it and the patient at least every other month. The physician sees the person as needed but not less than every other month. Rehabilitation nursing may be provided to monitor stability and provide education for the patient, family, and/or others.	A physician makes the referral for the needed rehabilitation services and gives a prescription for them. The physician sees the person as needed but on at least a monthly basis. The patient may be severely or slightly impaired. Rehabilitation nursing services are generally not provided.
Therapies & Services	Therapies and services are delivered pursuant to the plan of treatment. The intensity of delivery and frequency are dependent on the plan of care. They may be as frequent as 3 to 4 times per week or less.	Each discipline delivers its own services. One or more types of services may be delivered as frequently as 2 to 5 times per week depending upon the physicians' prescription. There is no formal coordination among the various disciplines delivering services.
Plan of Treatment	A plan of treatment is established and managed by the physiatrist or otherwise qualified rehabilitation physician and interdisciplinary team. It outlines the patient's anticipated goals, type, amount, frequency, and duration of services. It is reviewed and revised by the team at least monthly. Also, it is revised if there are other changes in the patient's condition.	The physician or other professional, depending upon the state, establishes and manages the plan of treatment regarding goals, type, amount, and duration of services for each discipline but not in a coordinated manner.

	9 **Residential Rehabilitation Programs**	10 **Vocational/Educational Programs**
Introduction	People in a residential treatment program are medically stable but they may be prone to more complications than the general public. An extensive program of coordinated therapies and services is provided. They may be self-referred or referred by insurance companies, discharge planners, case managers, families, or rehabilitation hospitals or units. Such programs may focus on a specific disability such as pain, arthritis, head injury, or spinal cord injury. Residential programs focus on returning the client to the community and living independently generally over a period of 6 to 18 months. Patients in these programs are referred to as "clients" in order to focus on the reintegration aspect of this part of medical rehabilitation.	Vocational rehabilitation and educational programs are outpatient programs. Medical rehabilitation is not the primary focus. The focus is on getting the person into or back into the work force or, depending on age and development, into school with an appropriate individual education plan, or back to an activie, meaningful retirement. Clients may be referred from other rehabilitation programs, state vocational rehabilitation agencies, insurance companies, state workers compensation programs, and other services. Clients may begin participating in a vocational/educational program at any time in their recovery. Only periodic medical checkups are provided, however, clients may require a greater amount of medical and personal support services than persons with disabilities. Vocational programs provide coordinated, integrated programs of vocational assessment, evaluation, training, adjustment, counseling, and placement. They also may include labor market analysis and vocational consultation. Limited medical rehabilitation services may also be provided. Vocational rehabilitation and educational programs are transitional programs which seek to move people back to work, back to school, or back to retirement activities through a series of phased programs. They may or may not be associated with a residential or medical rehabilitation program.
Where Does This Occur?	These programs are provided in or by transitional living centers, community reentry programs, or independent living centers.	These programs are usually found in vocational rehabilitation centers, special education programs, in public or private schools, vocational schools, residential programs, developmental centers, hospitals, or outpatient rehabilitation facilities with work evaluation, vocational evaluation, work hardening, or educational programs.
Components: Medical and Nursing Services	The program includes the availability of periodic, continued medical supervision and evaluation. General nursing services are available as needed.	Medical or nursing services are not generally provided or required.
Therapies and Services	Coordinated therapies and services are provided approximately 5 to 6 hours per day.	Vocational/educational services and other therapies and services are provided from 1 to 40 hours per week, depending on the patient's functional status and ability to tolerate vocational/educational services.
Plan of Treatment	A plan of treatment is established and managed by the interdisciplinary rehabilitation team which outlines the client's anticipated goals, type, amount, frequency, and duration of services. It is reviewed and revised by the team once a month. A member of the team is the designated program manager.	An assessment and a plan of treatment is established and managed by a rehabilitation counselor in consultation with other members of an interdisciplinary team.

IX. SELECTED REFERENCES

Vocational Rehabilitation of the Disabled: An Overview, D. Malikin and H. Ruralem, New York University Press, New York and University of London Press Limited, London, 1969.

Accreditation Manual for Hospitals 1988, Joint Commission on Accreditation of Hospitals, Chicago, Illinois, 1986.

Statement of Principles on Physician Services in Rehabilitation Hospitals and Units, National Association of Rehabilitation Facilities, Washington, D.C., 1985.

A Guide to Choosing A Comprehensive Inpatient Medical Rehabilitation Facility, AHA, Chicago, Illinois, January, 1987.

Functional Assessment in Rehabilitation Medicine, Granger and Gresham, Williams and Williams, Baltimore/London.

Medical Rehabilitation Services in Health Care Institutions, American Hospital Association, Chicago, Illinois, 1986.

Standards Manual for Facilities Serving People With Disabilities, Commission on Accreditation of Rehabilitation Facilities, Tucson, Arizona, 1986.

Questions to Consider When Seeking Medical Rehabilitation Services, Michiana Rehabilitation Institute of Memorial Hospital, South Bend, Indiana.

How to Choose a Physical Rehabilitation Program, Marianjoy Rehabilitation Center, Wheaton, Illinois, 1986.

Integrated Rehabilitation Services Model, La Ranchi and Perez, Casa Colina, Incorporated, Pomona, California, 1987 (unpublished).

Technical Assistance Document #24, *Sample Screening Criteria for Review of Admissions to Comprehensive Medical Rehabilitation Units/Hospitals*, Health Care Financing Administration, Department of Health and Human Services, Washington, D.C., 1981.

Sec. 211, *Medicare Hospital Manual*, Coverage Guidelines for Inpatient Rehabilitation Hospital Care, Health Care Financing Administration, Department of Health and Human Services, Washington, D.C.

X. QUESTIONS TO CONSIDER WHEN LOOKING FOR MEDICAL REHABILITATION

1. Does the facility specialize in rehabilitation?
2. How experienced is the facility in providing a rehabilitation program? How experienced is the staff?
3. Can the program provide teams with specialized expertise in treating specific conditions?
4. Is the facility staffed to provide an intense, competent rehabilitation program? How comprehensive is the program?
5. What percentage of the patients return to their home at the completion of their program?
6. What percentage of patients return to work at the completion of their program?
7. Is the program supervised by a physician trained in the field of rehabilitation medicine?
8. Do you feel the staff is sensitive to the unique needs of the individual patient?
9. What accreditation/certification standards does the facility have?
10. Are the consultants board certified in their particular specialty? Do they reside in the vicinity and do they respond promptly?
11. What specific rehabilitation services are available?
12. Do patients retain the same therapist(s) throughout their rehabilitative stay?
13. Does the facility employ the training staff or are they contracted from an outside agency?
14. Are there adequate and appropriate facilities to appropriately address the needs of the patient's condition?
15. Does the facility utilize preadmission criteria to assess the prospective patient's potential for rehabilitation?
16. Is discharge planning started early in the program?
17. Is the home evaluation/assessment provided by the rehabilitation team?
18. Does the program provide for trial home visits by patients?

19. Can families observe treatment?

20. Are the patient's family and/or the third-party payor representative encouraged to attend patient conferences and assist in patient care planning?

XI. TASK FORCE ON DIFFERENTIATING LEVELS OF CARE IN MEDICAL REHABILITATION

Bruce Schurman
Task Force Chairman
President & CEO
Marianjoy Rehabilitation Center
Wheaton, IL

Larry Cervelli
Chief Operating Officer
American Medical Services Rehab.
North Hampton, MA

Richard C. Craven
Administrator
Sheltering Arms Rehab Hospital
Richmond, VA

Ronald Diurba
Chief Operating Officer
Rehab Hospital Services Corp.
c/o NME Specialty Hosp. Group
Washington, D.C.

Harold J. Egli
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Michiana Rehab. Institute of
Memorial Hospital
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Barbara Gebhardt
Director Rehab Services
Fairfax Hospital Association
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Marsha Halpern
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Lincoln, NE

Karen Breckenridge
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New England Rehab Hospital
Woburn, MA

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Vice President & CEO
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Atlanta, GA

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Senior Director/Rehabilitation
Manor HealthCare Corporation
Silver Spring, MD

James Liljestrand, M.D.
Medical Director
Braintree Hospital
Braintree, MA

Lou Loescher
Coordinator/Rehab Services
St. Luke's Hospital of KS City
Kansas City, MO

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Medical Director
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Warren R. Slavin
Executive Vice President
Bon Secours Hospital
North Miami, FL

Carolyn Zollar
General Counsel/Associate Dir.
for Medical Rehabilitation
National Association of Rehabilitation Facilities
Washington, D.C.

Monograph Series

THE PAYORS OF MEDICAL REHABILITATION: ELIGIBILITY, COVERAGE AND PAYMENT POLICIES

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Author:
Andrew I. Batavia, J.D., M.S.

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(703) 648-9300

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Andrew I. Batavia, J.D., M.S.

Associate Director for Health Services Research
National Rehabilitation Hospital
Washington, D.C.

Adjunct Assistant Professor
Department of Community and Family Medicine
Georgetown University School of Medicine
Washington, D.C.

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FOREWORD

In this monograph, the National Association of Rehabilitation Facilities presents the most complete description to date of the public and private sector entities which pay for medical rehabilitation services and programs in the United States. The author, Andrew I. Batavia, explains in great detail the eligibility, coverage and payment policies of the major payors of medical rehabilitation and provides the reader the opportunity to understand more fully the mechanisms for its financing.

NARF appreciates the contribution of Mr. Batavia in advancing the understanding of medical rehabilitation.

Edmund S. McLaughlin
President, NARF

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ABOUT THE AUTHOR

Andrew I. Batavia is the Associate Director for Health Services Research at the National Rehabilitation Hospital (NRH) in Washington, D.C., and a member of the faculty of the Georgetown University School of Medicine. He is a health care attorney and policy analyst, specializing in the economics and financing of medical rehabilitation and other health care services for the disabled population. He received a Bachelor of Arts degree in Economics and Sociology from the University of California in 1980, a Master of Science in Health Services Research from Stanford Medical School in 1983, and a Juris Doctor degree from Harvard Law School in 1984.

From 1984 to 1986, Mr. Batavia served as an attorney for the Health Care Financing Administration, U.S. Department of Health and Human Services. In that capacity, he addressed a broad range of legal issues relating to the federal implementation of the Medicare and Medicaid programs, and developed an expertise in issues concerning Medicare's Prospective Payment System for inpatient hospital care. He has also published articles in the area of health care antitrust law.

In 1986, Mr. Batavia was awarded the Mary E. Switzer Distinguished Research Fellowship in Medical Rehabilitation Finance from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, to conduct research on the financing of medical rehabilitation services. This study on the rehabilitation financing policies of the payors of medical rehabilitation is one product of his research fellowship activities. His research has been based at the Research Program of the National Rehabilitation Hospital.

Since October 1987, Mr. Batavia has served as the Project Director for a study sponsored by The Robert Wood Johnson Foundation to determine the feasibility of developing a capitation financed, managed health care program to meet the post-rehabilitation needs of persons with severe disabilities. The project, based at NRH, addresses that hospital's health services research priority of studying and meeting the ongoing needs of persons with disabilities as consumers of health care services.

As a C2-3 quadriplegic, Mr. Batavia has gained a unique perspective on the provision of medical rehabilitation in this country. He received inpatient medical rehabilitation at the Rusk Institute of Rehabilitative Medicine in New York City in 1973, and has since visited and studied rehabilitation centers throughout the United States.

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This study was supported by the Mary E. Switzer Distinguished Research Fellowship in Medical Rehabilitation Finance from the National Institute on Disability and Rehabilitation Research (NIDRR). The author wishes to thank his Advisory Committee, Gerben DeJong, Ph.D., Edward A. Eckenhoff, M.H.A., Brent England, M.H.A., Alain C. Enthoven, Ph.D., Victor R. Fuchs, Ph.D., Edward F. Holden, M.H.A., Gail E. Schwartz, M.P.H., Thomas Stripling, and Steven Sieverts, M.S., for their valuable comments on this monograph. The author is further grateful to Carolyn Zollar, J.D. and Corrine Parver, J.D. of the National Association of Rehabilitation Facilities (NARF) for their excellent suggestions.

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The opinions expressed in this monograph (and any errors that might be contained within) are solely those of the author. They do not necessarily represent the views of NIDRR, NRH, NARF, AHA, HCFA, DHHS, the researcher's Advisory Committee, or any other individual, organization, or agency.

THE PAYORS OF MEDICAL REHABILITATION: ELIGIBILITY, COVERAGE, AND PAYMENT POLICIES

I. INTRODUCTION

A broad patchwork of public and private sector entities pay for medical rehabilitation services in the United States. These include the Health Care Financing Administration (HCFA) of the U.S. Department of Health and Human Services (DHHS), the Veterans Administration (VA), state vocational rehabilitation agencies, private health insurers, private disability insurers, self-insured corporations, health maintenance organizations (HMOs), other prepaid managed care providers, workers' compensation plans, and casualty insurers. In addition, medical rehabilitation services are financed through the charitable donations of organizations and individuals, the out-of-pocket payments of patients and their families, and the provision of uncompensated care by rehabilitation providers.[1]

Each of these payors has played an important role in the growth of the medical rehabilitation industry and the availability of medical rehabilitation services for disabled persons. Yet, although we know the entities and programs that are paying the medical rehabilitation bill, there is little understanding by the health care industry or the public of their rehabilitation financing policies. Such knowledge would provide valuable insight on potential mechanisms for financing rehabilitative care. This monograph considers the third-party payors of medical rehabilitation services and their rehabilitation financing policies.

This monograph has four parts. Part I provides a background on the financing of medical rehabilitation services and defines the current scope of inquiry. Part II describes and analyzes the rehabilitation financing policies of the major public sector programs that pay for medical rehabilitation services, including Medicare, Medicaid, veterans' health care programs, and state vocational rehabilitation programs. Part III focuses on the rehabilitation financing policies of the various private sector payors of medical rehabilitation, including private health, disability, and casualty insurers. Finally, Part IV draws conclusions from the overall analysis.

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[1] Although charitable donations, self-pay by patients, and "free" care by providers are important sources of payment for rehabilitation, they are not addressed at any length in this monograph. The monograph's primary purpose is to describe and analyze the formal and informal policies of third-party payors, such as health, disability, and casualty insurers.

A. Background and Importance

In the Social Security Amendments of 1983, Congress established the Medicare Prospective Payment System (PPS) for inpatient hospital care.[2] In enacting this legislation, Congress specifically exempted qualifying rehabilitation hospitals and rehabilitation units in acute care hospitals from payment under the system.[3] It recognized that the payment methodology of the Medicare PPS was based almost exclusively on the utilization experience and costs of acute care patients, and did not adequately consider the circumstances of medical rehabilitation patients or the rehabilitation facilities in which they receive care (NARF, 1984).[4] The PPS legislation required the Secretary of DHHS to report on the feasibility of establishing a prospective payment system for medical rehabilitation.[5]

In October 1987, DHHS released its Report to Congress entitled "Developing a Prospective Payment System for Excluded Hospitals." Among the Report's conclusions is that it is premature to develop legislative or regulatory recommendations for a PPS for rehabilitation (DHHS, 1987; Batavia and DeJong, 1988). A substantial debate has developed within the rehabilitation industry over the most appropriate payment system for the efficient and equitable provision of rehabilitative care. The basic issue is whether Medicare's DRG-based PPS, another type of prospective payment system, or a cost-based retrospective reimbursement system is most appropriate for payment of medical rehabilitation services at a rehabilitation hospital or unit (Hosek et al., 1986; Batavia, 1988).[6]

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[2] Section 601 of Pub. L. 98-21.

[3] Section 1886(d) of the Social Security Act. Also excluded under this section are children's hospitals, long-term hospitals, and psychiatric hospitals and units. The statutory exclusion for rehabilitation hospitals and units is contained in Section 1886(d)(1)(B). HCFA, which administers the Medicare Program, has promulgated regulations at Sections 412.23(b), 412.25, and 412.29 of Volume 42 of the Code of Federal Regulations, setting forth specific criteria that must be met for rehabilitation hospitals and units to be exempt from the PPS.

[4] The House Ways and Means Committee Report to the 1983 Social Security Amendments recognized that "the DRG system was developed for short-term acute care general hospitals and as currently constructed does not adequately take into account special circumstances of diagnoses requiring long stays" (NARF, 1984; H. Rept. 98-25).

[5] Section 603(a)(2)(C)(ii) of the Social Security Amendments of 1983.

[6] Since 1983, several studies have been conducted on rehabilitation providers and patients for purposes of developing an informed payment policy for medical rehabilitation (NARF, 1985; Hosek et

In addition to the payment for medical rehabilitation, Congress is concerned over such issues as poor access to health insurance for persons with disabilities and work disincentives for disabled persons under the Medicare and Medicaid programs (Gorski, 1985).7 In the Employment Opportunities for Disabled Americans Act,8 Congress addressed the problem of disincentives to work under Medicaid (Gorski, 1985).9 In the Rehabilitation Act Amendments of 1986,10 Congress mandated the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education to "conduct a study of health insurance practices and policies which affect individuals with handicaps."

With this high level of interest in "disability-related" health care issues, new approaches to financing the care of persons with disabilities are likely to be developed in the coming decades. The approaches adopted will have a major effect on access, cost, and quality of health care services for disabled persons. Thus, it is essential that any new mechanisms or systems focus on the broad interests of the disabled population, and of society as a whole. New systems should provide incentives for providers to furnish ready access to comprehensive, coordinated, and high quality care in a cost-effective manner, and should pay providers equitably for their services (Batavia, 1988).

Before new approaches to financing the health care of persons with disabilities can be developed, there must be a greater understanding of how such services are financed now. This monograph describes and analyzes the financing policies of the public and private sector payors of medical rehabilitation.

B. Scope of Inquiry

Medical rehabilitation is the field of health care that seeks to enhance the functional abilities of persons with disabilitics (Rusk, 1978; Kottke, 1982). A broad range of health care providers offer a wide variety of medical rehabilitation services. Independent freestanding rehabilitation hospitals and distinct-part rehabilitation units in acute care hospitals offer the most comprehensive, coordin-

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al., 1986; McGinnis et al., 1987). These studies generally confirm that the DRG- based Medicare PPS, as currently devised, is not appropriate for the payment of medical rehabilitation services. They do not conclude definitely what would be the most appropriate system (Batavia, 1988).

[7] Section 202(m) of the Rehabilitation Act Amendments of 1986, Pub. L. 99-506.

[8] Pub. L. 99-643.

[9] Congress did so by making permanent Section 1619 of the Social Security Act (discussed below in Section II.B.).

[10] Pub. L. 99-506.

ated, and intensive medical rehabilitation services. Other providers such as acute care hospitals, skilled nursing facilities, intermediate care facilities, and a variety of outpatient and home health agency providers also offer medical rehabilitation services (Eckenhoff, 1980; Eckenhoff, 1986; England, 1986; Batavia, 1988).

This monograph addresses the financing policies of the major payors of medical rehabilitation as they apply to all providers of medical rehabilitation services. For purposes of the analysis, medical rehabilitation is defined broadly as:

> the provision of all services in any inpatient, outpatient, office or home setting by, or under the supervision of, medically certified professionals and paraprofessionals for the purpose of reducing the functional limitations of individuals with physical impairments (or physical and mental impairments resulting from brain injury or stroke) (Batavia, 1988).

In analyzing each payor of medical rehabilitation, three broad policy components are considered: (1) eligibility, (2) coverage, and (3) payment for rehabilitative care.[11] Although potential methods of payment for rehabilitation services now are receiving most attention, eligibility and coverage policies are at least as important in determining access to rehabilitation services. The current analysis considers each payor's provisions for eligibility as well as for coverage and payment of the following twelve rehabilitation services:

- o physicians' services;
- o physical therapy;
- o occupational therapy;
- o speech-language pathology;
- o respiratory therapy;
- o prosthetics;
- o orthotics;
- o social services;
- o psychological services;
- o rehabilitation nursing;
- o drugs and biologicals;
- o supplies, appliances and equipment.

---

[11] These terms are defined as they are used in the federal Medicare and Medicaid programs. "Eligibility" refers to whether a particular individual is entitled to receive benefits under the program;.

"Coverage" refers to whether a particular type of service (e.g., physical therapy) generally qualifies for payment under the program;, as well as whether a particular service actually provided qualifies for payment. 42 C.F.R. Section 409.3. However, the phrase "to cover" also is used to connote eligibility when referring to coverage of people as opposed to services (i.e., "many disabled persons are covered under Medicaid").

"Payment" refers to the specific mechanism (e.g., cost-based reimbursement or DRG-based payment) by which a covered service is paid on behalf of an eligible individual.

In addition to the twelve services listed, rehabilitation providers often furnish rehabilitation engineering services, dietary services, and a multitude of other clinical and administrative services. These services are essential components of a comprehensive rehabilitation program such as that offered at a rehabilitation hospital, but are not formally included in the current analysis, either because they are typically not covered by third-party payors or they are reimbursed only indirectly as part of a provider's overhead.12 Further research is needed to determine whether these important components of a rehabilitation program should be included as separately reimbursable services under public and private sector policies.

Most data collected on the provision and financing of medical rehabilitation services address only those services provided by independent rehabilitation hospitals and distinct-part rehabilitation units at acute care hospitals. The 1986 AHA Survey of Rehabilitation Hospitals and Units (hereafter, the AHA Survey) also considered rehabilitation services provided at acute care hospital units other than rehabilitation units (Sonik, 1988). Tables I and II, on page 6, derived from the results of the AHA Survey, indicate the sources of payment and percentage of revenues in 1985 for rehabilitation hospitals, rehabilitation units, and other rehabilitation services provided in acute care hospitals.13 They show that Medicare and Medicaid combined account for just over half of the inpatient revenues, and account for about a third of the outpatient revenues of medical rehabilitation providers in this country. The smaller public sector payors and the private sector payors pay the vast majority of the remainder. Other studies support these results (NARF, 1985; Hosek et al., 1986).

Much research still is needed on the provision and financing of medical rehabilitation services at long-term care facilities, such as skilled nursing facilities (SNFs), intermediate care facilities (ICFs), and long-term care hospitals. Also, relatively little is known about the financing of rehabilitative care at such outpatient rehabilitation settings as Comprehensive Outpatient Rehabilitation Facilities (CORFs), rehabilitation agencies, private rehabilitation practices, and patients' homes.

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12 This analysis also does not specifically address the financing of assistive devices for persons with disabilities, a topic closely related to the financing of rehabilitation engineering services. The payors of assistive devices and their financing mechanisms have been addressed elsewhere (Mittelmann and Settele, 1982; Reeb, 1987a; Reeb, 1987b; Reeb, 1987c; Reeb, 1987d; Scadden, 1987).

13 The AHA Survey compiled 1985 data on rehabilitation hospitals, units, and services (Sonik, 1988).

Table I

Sources of Gross Inpatient Revenues

	Rehab hospital revenue %	Rehab Unit revenue %	Rehab Services Revenue %
Medicare	39.57	52.57	38.61
Medicaid	16.11	13.94	23.57
Vocational Rehabilitation	1.29	.74	.06
Other Fed, State and Local	3.12	1.43	2.51
Blue Cross/ Blue Shield	10.86	9.95	5.80
Commercial Insurance	6.20	9.29	19.62
Workers' Compensation	1.62	.63	1.07
HMOs, PPOs, and PPAs	.36	.90	2.78
Self Pay	3.00	2.31	1.24
Other	7.87	8.24	4.71
TOTAL %	100.00	100.00	100.00
TOTAL DOLLARS (in millions)	621.43	561.26	9.01

Table II

Sources of Gross Outpatient Revenues

	Rehab hospital revenue %	Rehab Unit revenue %	Rehab Services Revenue %
Medicare	24.73	22.68	28.65
Medicaid	15.62	8.76	8.50
Vocational Rehabilitation	1.11	2.69	.17
Other Fed, State and Local	.82	6.97	.55
Blue Cross/ Blue Shield	13.46	13.00	21.13
Commercial Insurance	23.62	13.19	16.91
Workers' Compensation	4.16	8.84	7.21
HMOs, PPOs, and PPAs	.51	3.62	4.58
Self Pay	7.34	9.89	3.83
Other	8.63	12.88	8.41
TOTAL %	100.00	100.00	100.00
TOTAL DOLLARS (in millions)	67.01	39.72	5.89

* These percentages and dollar amounts were derived from the results of the 1986 AHA Survey (Sonik, 1988). Percentages were calculated to .01%. Due to rounding error, percentage totals may not equal 100%.

II. PUBLIC SECTOR PAYORS OF MEDICAL REHABILITATION

Study of the public sector payors of medical rehabilitation is particularly important, because the public sector finances the majority of medical rehabilitation services in this country. In addition, public sector payors strongly influence the policies of each other and of the private sector payors of rehabilitation.14 The major public sector payors of medical rehabilitation are:

a) the federal government through the Medicare program;

b) the federal and state governments through the Medicaid program;

c) the Veterans Administration; and

d) state vocational rehabilitation agencies.15

Some medical rehabilitation services are financed by the various levels of government through the Education for All Handicapped Children Act16, "free care" under the Hill-Burton Act17 and a variety of small state and local health care programs. Although these smaller sources of rehabilitation funding are not addressed further in this monograph, they must be considered as part of the current fragmented approach to the financing of medical rehabilitation and health care

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14 Under federal administrative law, federal agencies such as HCFA and the VA generally must publish the regulations of their programs in the Federal Register. Such regulations are compiled and updated annually in the Code of Federal Regulations (C.F.R.). In this monograph, reference to 42 C.F.R. section 412.23, for example, signifies that the regulation considered may be found in Section 412.23 in Part 412 of Title 42 of the Code of Federal Regulations.

15 Workers' compensation, also a major payor of medical rehabilitation, is often considered a public sector program, because it is mandated and heavily regulated by state governments. Because it is typically administered on a for-profit basis by private sector casualty insurers, this monograph treats workers' compensation in Part III as a private sector payor of medical rehabilitation.

16 Under Pub. L. 94-142, some rehabilitation professionals and providers contract with school systems to provide services to disabled children.

17 See Title 6 of the Public Health Service Act. Provision of uncompensated care is one of the obligations incurred by providers that accepted funding for construction or modernization of their hospitals under the Hill-Burton Act. 42 U.S.C. Section 291j-3(b)(3).

services generally in this country. The following sections describe the rehabilitation-related policies of the major public sector programs that pay for medical rehabilitation services.18

A. Medicare

Title XVIII of the Social Security Act provides for the federal program of Health Insurance for the Aged and Disabled, known as Medicare.19 Medicare is divided into two parts: Part A and Part B. Medicare Part A, the Medicare Hospital Insurance Program, primarily covers inpatient hospital, skilled nursing facility (SNF), home health agency, and medical rehabilitation services. It is funded through the mandatory contributions of employers and employees to the Social Security Hospital Trust Fund. Medicare Part B, the Medicare Supplemental Medical Insurance Program, primarily covers physician and outpatient services. It is funded, in large part, through the premium contributions of Medicare beneficiaries who enroll in Part B. Although an eligible Medicare applicant is automatically enrolled in Medicare Part A, the applicant must decide whether to enroll in, and thereby incur an additional premium for, Part B.

Medicare covers a broad range of health care services for its eligible beneficiaries. Medicare beneficiaries are required under the program to pay out-of-pocket expenses for the Medicare deductible, copayments, and services that are not covered under the program. The cost to the beneficiary of these out-of-pocket expenses can amount to thousands of dollars. Therefore, many Medicare beneficiaries supplement their Medicare benefits with private health insurance policies, sometimes called "MediGap" policies. These policies pay for deductibles, copayments, and other amounts that the Medicare beneficiary would otherwise have to pay out-of-pocket (SSA, 1986).

Medicare is the single largest payor of medical rehabilitation services in the United States. For eligible individuals, Medicare covers certain inpatient and outpatient rehabilitation services provided at a rehabilitation hospital or unit, an acute care hospital, SNF, CORF, rehabilitation agency, therapist's office, or at the patient's home (through the services of a home health agency). As indicated in Table I, Medicare contributes approximately 39.5 percent of rehabilitation

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18 The policies are described as they existed at the time that this monograph was published. Because program policies frequently change through amendments to statutes and modifications to regulations and manual provisions, it is necessary for the reader to verify that policies of interest to them are current. Footnote citations will assist readers in researching policy modifications. For the reader interested in obtaining a general understanding of the programs as they relate to rehabilitation, the following sections of this monograph will provide a broad overview.

19 42 U.S.C. Sections 1800 _et seq_.

hospital, 52.5 percent of rehabilitation unit, and 38.6 percent of other gross inpatient revenues for medical rehabilitation services (Sonik, 1988).

1) Eligibility for Medicare benefits

Eligibility for Medicare Part A generally results from entitlement to monthly cash benefits from one of the programs under Title II of the Social Security Act.[20] Under Section 226 of that Act, an individual is entitled to Medicare hospital insurance benefits if over 65 years of age, and eligible for monthly cash benefits under the federal Old Age and Survivors Insurance Program (OASI, popularly called "Social Security.")[21] Individuals under age 65 who are entitled to payment under the Social Security Disability Insurance (SSDI) program[22] may also become eligible for Medicare (SSA, 1986).[23]

Most Medicare beneficiaries who receive medical rehabilitation services are persons over age 65 who are eligible for Medicare by virtue of receiving OASI retirement benefits under Social Security. This is, in part, because a large proportion of persons who require medical rehabilitation services are elderly people with chronic, disabling diseases. Rehabilitation patients who are Medicare-eligible through OASI most often require medical rehabilitation services for recovery from strokes (the most common diagnosis for medical rehabilitation) or hip fractures (NARF, 1985).

A much smaller number of persons who receive medical rehabilitation under Medicare are eligible for Medicare based on their eligibility for SSDI. To be SSDI-eligible, an individual with recent Social Security-covered employment[24] must be unable to engage in any "substantial gainful employment by reason of a medically determinable physical or mental impairment which can be expected to last for a continuous period of not less than 12 months."[25] The SSDI applicant must also complete a five-month waiting period before receiving cash benefits under SSDI,[26] and an additional 24-month waiting period before becoming eligible for Medicare.[27]

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[20] 42 C.F.R. Section 408.6. Sections 226, 226A and 1818 of the Social Security Act establish the general conditions for eligibility for benefits under Medicare Part A.

[21] The Medicare provisions for eligibility and entitlement are contained in 42 C.F.R Part 408. Provisions for entitlement to OASI benefits are contained in Section 202 of the Social Security Act. In addition to OASI recipients, Section 103 of Pub. L. 98-89 provides for the eligibility of certain other groups described in 42 C.F.R. Section 408.11.

[22] The provisions on SSDI are found in Title II of the Social Security Act.

[23] 42 C.F.R. Section 408.12.

[24] The requirement of recent covered employment is contained in Section 223(c) of the Social Security Act. Generally, workers who are 31 years old or over must have 20 quarters of coverage during the preceding 40 quarters, and workers under age 31 must have been covered for at least one half of the quarters since they reached age 21 (but no fewer than 6 quarters).

The strict definition of disability used by Social Security and the 24-month waiting period substantially limit the number of non-elderly disabled persons receiving medical rehabilitation services under Medicare.[28] The first restriction limits the total number of disabled people eligible for Medicare; the second delays eligibility to a time substantially after the onset of the disability, potentially reducing the benefits of rehabilitation.[29] In some cases, the disabled person is able to receive rehabilitation through alternative funding programs prior to the end of the 24-month waiting period.

2) Medicare Coverage and Payment for Medical Rehabilitation

Any health care provider that satisfies applicable Medicare "Conditions of Participation" and signs a Medicare provider agreement with HCFA may receive payment for covered services to eligible individuals under the Medicare Program. Medicare regulations set forth the specific types of services, including medical rehabilitation, covered under the program.30 Medicare covers health care services only if deemed reasonable and necessary with respect to efficacy, duration, frequency, and amount. The method of payment for such services depends upon the type of service provided and the type of provider that furnished it (SSA, 1986).

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[25] Section 223(d)(1)(A) of the Social Security Act.

[26] Sections 223(a)(1) and 223(c)(2) of the Social Security Act.

[27] Section 226(b)(2)(A) of the Social Security Act. There is, however, an exception to the waiting period for End Stage Renal Disease (ESRD) patients under Section 226(a) of the Act.

[28] The reasons for the seeming paradox of a disability pension program that denies its beneficiaries the rehabilitation services that could remove them from the program rolls and save the program money lie in the SSDI program's historical links to the Old Age and Survivors Insurance program. Congress conceived the disability program, like the Old Age program onto which it was grafted, as a cash benefit program for persons who clearly could not be expected to resume working and for whom rehabilitation was thought to be of little practical value. This rationale appears inappropriate and outdated today, particularly considering studies now indicating the effectiveness of rehabilitation in returning the disabled population to work (See Eazell and Johnson, 1981; Johnson and Keith, 1983).

[29] The 24-month waiting period is an important concern, because it is generally believed that medical rehabilitation is of greatest benefit to the patient directly after the patient is stabilized in acute care. The benefits may be reduced and costs increased if medical rehabilitation is delayed for a long period of time after the onset of disability (Kottke, 1982).

Most Medicare providers are the traditional "fee-for-service" providers of health care, such as hospitals, physicians, and home health agencies. In addition, Medicare permits prepaid health care plans, such as health maintenance organizations (HMOs), independent practice associations (IPAs), and competitive medical plans (CMPs) to contract to provide services to Medicare beneficiaries. They may contract either on a risk (i.e., prepaid) basis or on a cost (i.e., retrospective reimbursement) basis. Prepaid plans receiving Medicare reimbursement under a risk contract must provide all benefits available under Part A and Part B, including inpatient and outpatient rehabilitation services, either directly or through contract providers. The provision of medical rehabilitation by HMOs and other prepaid plans is addressed further in Part III.

Like other health insurance programs, Medicare uses "coordination of benefits" rules to avoid duplicative payments to providers for the same services provided to a beneficiary. Such provisions specify which payor is primarily liable if the individual's services are covered under more than one program. Medicare's rules provide that payment may not be made for any item or service if payment has been made, or could reasonably be expected to be made, under a federal or state workers' compensation program, under automobile insurance (including no-fault), or under any other form of liability insurance.31 Further, Medicare benefits are generally secondary to benefits available under employer group health plans.32

The following sections summarize Medicare's coverage and payment policies applicable to providers of medical rehabilitation services.

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30 There are different conditions of participation for each type of Medicare provider. The conditions for Medicare hospitals (which are applicable to rehabilitation hospitals, as well as short-term hospitals) are set forth at 42 C.F.R. Section 405, Sub-part J. Section 405.1031(d) of that Sub-part requires that, _if_ a hospital has a rehabilitation, physical therapy, or occupational therapy department, it must meet specified standards to ensure adequate services and staffing for those departments. On the other hand, SNFs _must_ offer certain specified rehabilitation services under 42 C.F.R. Section 405.1126 to qualify as a Medicare provider.

31 42 C.F.R. Sections 405.316 through 405.321 contain the provisions for non-reimbursement of expenses for which workers' compensation is liable. Sections 405.322 through 405.325 contain the provisions addressing automobile and liability insurance.

32 42 C.F.R. Sections 405.340 through 405.342.

a) Inpatient rehabilitation in acute care hospitals

Since the establishment of Medicare in 1965, inpatient services provided in acute care hospitals have been covered by the program.33 Until 1983, Medicare Part A reimbursed hospitals for inpatient care based upon retrospective (i.e., after services were provided) determinations of their reasonable costs incurred (DHHS, 1982).34 In 1983, largely in response to the belief that cost-based retrospective reimbursement offers incentives for providers to increase costs and provide services inefficiently, Congress replaced this system with the Prospective Payment System (PPS) for inpatient hospital care (DHHS, 1982; DHHS, 1987).35

Under Medicare's PPS, each participating hospital is entitled to a fixed predetermined payment per discharge for each of its Medicare inpatients, based primarily upon the patient's classification into a diagnosis-related group (DRG). The DRGs comprise 367 diagnostic categories which classify patients according to such factors as primary diagnosis, secondary diagnoses, procedures utilized, and discharge disposition. Each DRG was developed to classify inpatients in a medically meaningful manner based on their use of similar medical resources (Fetter et al., 1985).

Payment per DRG under Medicare is intended to reflect the average resources utilized, and thus the average costs incurred, for the average Medicare patient classified in a DRG. The PPS was designed, using a prospective determination of DRG-based payment rates, to give providers an incentive to contain costs. If a hospital contains its costs within the DRG payment for a patient's inpatient stay, it keeps the difference between the payment and its costs; if it incurs costs above the payment for a patient, it incurs a loss for that patient (DHHS, 1982).

Prior to the implementation of the Medicare PPS, each Medicare-covered inpatient rehabilitation service (as any other covered inpatient clinical service) was reimbursed separately on a reasonable cost basis.

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33 The inpatient services covered and the scope of hospital insurance benefits under Medicare Part A are set forth at 42 C.F.R. Part 409, Sub-parts B and F, respectively.

34 The statutory definition of cost-based reimbursement is set forth at Section 1861(v) of the Act, and the principles of reasonable cost reimbursement are contained at 42 C.F.R. Part 413. The reimbursement of reasonable costs was (and is) also subject to certain deductibles and coinsurance paid by Medicare beneficiaries. Provisions on the Medicare inpatient deductible and coinsurance (still applicable under the Medicare PPS) are set forth at 42 C.F.R. Part 409, Sub-part G.

35 Section 601 of the Social Security Amendments of 1983, Pub. L. 98-21. The regulations on Medicare's PPS are contained in 42 C.F.R. Part 412.

This has changed with the implementation of the PPS. Hospitals now receive a single DRG payment for all services provided to a patient as part of a patient's inpatient care, including all rehabilitation services (except for rehabilitation services provided in a rehabilitation unit qualifying for PPS exclusion, as discussed in the following section).[36] DRG 462 is the diagnosis-related group for a rehabilitation diagnosis. Thus, although Medicare still covers rehabilitation services in an acute care hospital, it no longer pays separately for the cost of each service provided (DHHS, 1982; DHHS, 1987; NARF, 1988).[37]

b) Inpatient comprehensive rehabilitation

The most intensive providers of comprehensive medical rehabilitation are freestanding rehabilitation hospitals and distinct-part rehabilitation units in acute care hospitals. In addition to the general requirements applicable to acute care hospitals, these "comprehensive rehabilitation" providers must meet several requirements to receive payment for inpatient care under Medicare. It must be reasonable and necessary that the care they provide to their patients is provided at a comprehensive rehabilitation facility, rather than at a SNF, ICF, or other facility. Patients admitted to rehabilitation hospitals and units must require 24-hour availability of rehabilitation physicians and nurses; intensive physical and occupational therapy at least three hours per day; other related therapies and services; and a coordinated program of care delivered by a multi-disciplinary team.

Under the Social Security Amendments of 1983, inpatient rehabilitation hospitals and units (as defined by the Secretary of DHHS) were explicitly "excluded" from payment under the DRG-based prospective payment system.[38] The term "excluded," as used in the legislation, is less appropriate than the term "exempted," because facilities that qualify for an "exclusion" must choose whether to opt out of the PPS. If they do not opt out, they are included in the system. DHHS, through HCFA, established criteria published in federal regulations for determining which of these facilities may claim an exemption from the PPS.39

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[36] Rehabilitation hospitals (as well as children's, psychiatric, and long-term care hospitals) and rehabilitation units (as well as psychiatric units) in acute care hospitals are currently exempt from the Medicare PPS. Criteria for exclusion are contained in 42 C.F.R. Part 412, Sub-part B.

[37] Anecdotal evidence suggests that, since the implementation of the DRG system, hospitals are discharging patients earlier than ever before, and patients who are not medically stable are entering medical rehabilitation hospitals (Zollar, 1985). In addition, one preliminary study provides some statistical support for rehabilitation industry allegations that patients are being admitted to rehabilitation "quicker and sicker" (Costich, 1985; Costich, 1987). If such contentions are true, the DRG system may not be reducing costs, but only transferring them from one type of health care provider to another (Batavia, 1988).

[38] All Medicare-participating hospitals that have not been explicitly excluded by Congress from payment under the Medicare PPS are currently paid on the basis of DRGs. The "exclusion" for rehabilitation hospitals and units from payments under the Medicare PPS is contained in Section 1886(d)(1)(B) of the Social Security Act.

To be exempt from payment under the Medicare PPS, rehabilitation hospitals and units must meet the following requirements:

- o They must be primarily engaged in furnishing medical rehabilitation, having treated within the previous year a minimum of 75 percent of their inpatients for at least one of ten conditions (stroke, spinal cord injury, congenital deformity, amputation, major multiple trauma, fracture of femur, brain injury, polyarthritis, neurological disorders, and burns).
- o They must have a pre-admission screening procedure to determine whether patients will benefit from an intensive rehabilitation program. They must further ensure that patients receive close medical supervision, using qualified personnel in rehabilitation nursing, physical therapy, and occupational therapy, and as needed, speech-language pathology, social or psychological services, and orthotic and prosthetic services.
- o They must have a physician director of rehabilitation trained or experienced in caring for patients who require inpatient rehabilitation services. They must have a plan of treatment established, reviewed, and revised by a physician for each inpatient, and use a multi-disciplinary team approach for each patient.
- o Rehabilitation units must be separate cost entities within the larger institution, and must not allow their beds to be used by acute care patients.

Rehabilitation hospitals and units that satisfy the HCFA exclusion criteria continue to be reimbursed retrospectively on the basis of reasonable costs for inpatient hospital operating costs incurred.40 Their reimbursable costs are, however, still subject to limits imposed by the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA).41

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[39] The DHHS exclusion criteria for rehabilitation facilities are contained in 42 C.F.R. Section 412.23(b) for rehabilitation hospitals, and Sections 412.25 and 412.29 for rehabilitation units.

[40] Reasonable costs are defined to include all necessary and proper costs (i.e., costs that are appropriate in developing and maintaining the operation of patient care facilities and operations) determined in accordance with regulations establishing an accounting methodology and items to be included. 42 C.F.R. Section 413.9.

[41] The provisions on the TEFRA limits on cost reimbursement are contained at 42 C.F.R. Part 413, Sub-part C.

TEFRA extended Medicare's previous per diem cost reimbursement limits to cover total inpatient operating costs per discharge. It also established a system of target ceiling limits with annual increases applied on a per discharge basis. Exempt hospitals and units receive a limited incentive payment if they do not exceed the target rate, and do not receive additional reimbursement if they exceed the target. The overall effect of the TEFRA is to establish a "target" inpatient operating cost per discharge for each hospital, thus creating an incentive within the retrospective cost-based system for providers to perform more efficiently (NARF, 1982; NARF, 1988).

HCFA has indicated its desire to bring medical rehabilitation under some form of prospective payment system (DHHS, 1987). Studies suggest, however, that the current DRG-based Medicare PPS is not appropriate for payment of medical rehabilitation (NARF, 1985; Hosek et al., 1986; McGinnis et al., 1987; Batavia, 1988).42 It appears that medical rehabilitation will retain its exemption from the current Medicare PPS at least until additional empirical research has been conducted on the appropriateness of applying an alternative payment model to rehabilitation, and until an appropriate new system can be developed (DHHS, 1987; Batavia and DeJong, 1988).

c) Post-hospital rehabilitation at SNFs

In addition to inpatient rehabilitation at acute care hospitals and comprehensive rehabilitation at rehabilitation hospitals and units, Medicare covers some inpatient rehabilitation services provided after a patient is discharged from the acute care or rehabilitation hospital. Medicare Part A covers physical therapy, occupational therapy, and speech-language pathology provided in a SNF after hospitalization.43 Such post-discharge SNF care is covered only if the patient requires a level of care demanding either skilled nursing or skilled rehabilitation services on a daily basis for a condition for which the patient was recently hospitalized.44

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42 The conclusions of these studies and a theoretical analysis of potential payment models for rehabilitation have been addressed elsewhere (Batavia, 1988).

43 See 42 C.F.R. Sections 405.165 through 405.167, 409.23 and 409.621(b). One of the conditions of participation for SNFs, set forth at 42 C.F.R. Section 405.1126, is that they must provide (or make arrangements to provide) certain specialized rehabilitation services, including rehabilitation nursing, physical therapy, speech-language pathology and audiology, and occupational therapy for patients that require such services. Such services must be provided under a written plan of care, initiated by an attending physician.

44 42 C.F.R. Sections 409.31 through 409.33. 42 C.F.R. Section 405.1632 requires that a physician certify and periodically recertify that SNF services are appropriate for the patient. See Section 1812(f)(1) of the Social Security Act.

d) Outpatient hospital-based rehabilitation

Since 1965, outpatient physical therapy services provided at a hospital or SNF have been covered under Medicare Part B.[45] Medicare Part B also covers outpatient speech-language pathology services provided at a hospital or SNF if such services would be covered on an inpatient basis under Medicare Part A.[46] In addition, outpatient physical therapy and speech-language pathology services are covered when provided at a clinic, rehabilitation agency or public health agency.[47] The Omnibus Budget Reconciliation Act of 1986 added occupational therapy to this list of covered outpatient services.

Generally, under Section 1814(b) of the Social Security Act (for Part A services not under the PPS) and under Section 1833(a)(2) (for Part B services), Medicare pays providers the lesser of their reasonable costs or customary charges for outpatient services. This is referred to as reimbursement on a charge basis.[48] Outpatient physical therapy and speech-language pathology services are generally payable on a charge basis under Medicare Part B as services "incident to" the services of a physician. They are reimbursable on a reasonable cost basis (not reduced by lower customary charges) when furnished by a participating clinic, rehabilitation agency, or public health agency.

e) Other outpatient rehabilitation (including CORFs)

Until 1980, the only outpatient rehabilitation services covered by Medicare were physical therapy, speech-language pathology, and the provision of certain durable medical equipment and prosthetic devices. These services typically had to be provided as part of a hospital or SNF-based outpatient program. Physical therapy services provided by (or under the direct supervision of) a qualified physical therapist in an independent practice also are covered up to a maximum of $500 per beneficiary per calendar year.[49] In 1980, after considerable efforts by NARF, Congress determined that it could enhance access to outpatient rehabilitation services and counter the high costs of hospital-based services by expanding coverage of non-hospital-based outpatient services (NARF, 1986).

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[45] Outpatient physical therapy provided at hospitals or skilled nursing facilities are covered as "medical and other health services" under 42 C.F.R. Section 405.231(1)(3).

[46] 42 C.F.R. Section 405.231(m)(2) and 405.231(j)(2).

[47] The Medicare Conditions of Participation for clinics, rehabilitation agencies, and public health agencies are contained at 42 C.F.R. Part 405, Sub-part Q. Under Section 405.1702(h), a rehabilitation agency is "an agency which provides an integrated, multi-disciplinary program designed to upgrade the physical function of handicapped, disabled individuals by bringing together as a team specialized rehabilitation personnel" and "which in addition to physical and speech pathology services [as required services], includes social or vocational adjustment services." Specific Conditions of Participation for rehabilitation agencies are provided at 42 C.F.R. Section 405.1720.

[48] The provisions for reimbursement on a charge basis are contained in 42 C.F.R. Section 413.13.

In Section 933 of the Omnibus Reconciliation Act of 1980 (ORA), for the first time, Congress recognized "comprehensive outpatient rehabilitation facilities" (CORFs) as providers qualifying for reimbursement under Medicare Part B.[50] CORFs are non-residential facilities specializing in the provision of medical rehabilitation services. The purpose of the CORF legislation was to create a new type of Medicare provider capable of furnishing coordinated comprehensive rehabilitation services on an outpatient basis. HCFA added the requirement in the CORF regulations that all CORF services must be provided at a single location (NARF, 1986). The Omnibus Budget Reconciliation Act of 1987[51] removed this restriction on the delivery of off-site physical therapy, occupational therapy, and speech-language pathology services, effective December 22, 1987.

Medicare covers all twelve basic rehabilitation services when provided at CORFs (as well as one home environmental evaluation provided by the CORF at the patient's home).[52] Medicare does not cover CORF services that are not reasonable and necessary, or that would not be covered if provided on an inpatient basis by a hospital under Medicare Part A.[53] In addition, CORF services are covered only if:

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[49] 42 C.F.R. Section 405.231(1)(2). The regulations pertaining to services furnished by physical therapists in independent practice are contained in 42 C.F.R. Sections 405.1730 through 405.1737. All such services are reimbursed by Medicare on a charge basis. Section 1833(g) of the Social Security Act imposes the reimbursement limit of $500 per beneficiary per calendar year.

[50] Section 933 of ORA, Pub. L. 96-499, established Section 1861(cc) of the Social Security Act, which provides for CORFs. The HCFA regulations on CORFs are set forth as a final rule in 47 *Federal Register* 56281 (December 15, 1982). For an excellent summary of all requirements for the certification and reimbursement of CORFs, *see* NARF, 1986.

[51] Pub. L. 100-203.

[52] 42 C.F.R. Section 405.260.

[53] 42 C.F.R. Section 405.261.

1) the patient is referred to the CORF by a physician who certifies that the patient needs skilled rehabilitation services;

2) the services are provided at the CORF's facility (except for the one home evaluation visit and certain physical therapy, occupational therapy, and speech-language pathology services) under the care of a physician; and

3) services are provided in accordance with a written plan of treatment periodically reviewed by a physician at the CORF.54

Services provided at CORFs are reimbursable on a reasonable cost basis, less applicable Medicare Part B deductibles and coinsurance.55 In addition, CORFs may charge a beneficiary up to 20 percent of their reasonable charges. CORFs are not subject to the lesser of costs or charges provision applicable to most other outpatient providers (NARF, 1986).56

To qualify for reimbursement, a CORF (as any Medicare provider) must satisfy all requirements for participation in the Medicare program.57 Among the participation requirements for CORFs are that they engage primarily in providing outpatient diagnostic and rehabilitative services, provide at least physicians' services, physical therapy, and social or psychological services, and provide all patient care under the supervision of a physician.58 Once certified, CORFs are paid for the provision of reasonable and necessary services rendered pursuant to their written plans of treatment. A physician must verify that skilled rehabilitation services were needed and provided under the patient's written plan (NARF, 1986).59

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54 42 C.F.R. Section 405.262.

55 Section 942 of OBRA provided that CORF services be reimbursed on a reasonable cost basis. "Reasonable costs" is defined for this purpose in Section 1861(v)(1)(A) of the Social Security Act and at 42 C.F.R. Part 405, Sub-part D of the federal regulations.

56 42 C.F.R. Section 405.455(a) makes clear that CORFs are not subject to the "lesser of reasonable cost or customary charges" reimbursement limitation applicable to other Medicare Part B providers.

57 The Medicare Conditions of Participation for CORFs are contained in 42 C.F.R. Part 485, Sub-part B. These regulations reiterate and supplement the statutory standards set forth in Section 1865 of the Social Security Act.

58 In addition, CORFs must satisfy any applicable state requirements for a certificate of need (CON). See Section 1861(cc) of the Social Security Act.

59 42 C.F.R. Section 405.1635.

f) Home-based rehabilitation

Medicare Parts A and B cover certain "home health services," defined narrowly as services furnished by or under arrangements made by a Medicare qualifying home health agency (HHA)[60] to an individual under the care of a physician in accordance with a written plan of care.[61] Such services are almost always provided at the patient's home, although they may, under limited conditions, be provided on an outpatient basis at a hospital, SNF, or rehabilitation center under arrangements made by a participating HHA.[62]

At one time, Medicare Part A covered 100 home visits during the one year period after a patient's discharge from a qualifying inpatient stay.[63] Medicare Part B separately provided coverage for up to 100 home visits per calendar year,[64] irrespective of whether the beneficiary has been in a hospital or SNF, and reimbursed 100 percent of the reasonable cost of such services.[65] The Medicare and Medicaid Amendments of 1980[66] have since removed the 100 day limits for home visits, such that all home visits that are reasonable and necessary are covered. Among the rehabilitation services included as "home health services" are physical therapy, occupational therapy, and speech-language pathology.[67]

Medicare Part B also covers certain rehabilitation services other than "home health services" provided at the patient's home. It covers physical therapy services provided by or under the direct supervision of a qualified physical therapist not affiliated with a home health agency, and reimburses such services on a charge basis.68 In addition, it covers the rental or purchase of durable medical equipment such as wheelchairs, and the purchase of prosthetic devices such as artificial arms and legs, and pays for such items on a charge basis (SSA, 1986).69

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[60] The Medicare Conditions of Participation for home health agencies are contained at 42 C.F.R. Section 405, Sub-part L. Section 405.1225 sets forth specific requirements for rehabilitative therapy services provided by HHAs if they offer such services.

[61] 42 C.F.R. Section 405.234. See 42 C.F.R. Sections 405.233 through 405.239, 405.1633.

[62] 42 C.F.R. Section 405.235.

[63] See 42 C.F.R. Section 405.170 for conditions of payment for home health services.

[64] Under 42 C.F.R. Section 405.239, Medicare beneficiaries have the option to treat physical therapy and speech therapy services that qualify as "home health services" as "medical and other health services," so as to preserve their limited number of covered home health services.

[65] 42 C.F.R. Section 405.240(C)(2).

[66] Pub. L. 96-499.

[67] 42 C.F.R. Part 409, Sub-part E.

B. Medicaid

Section XIX of the Social Security Act comprises the federal program of "Grants to States for Medical Assistance Programs," generally called Medicaid.70 Medicaid authorizes payment of federal funds to states (as well as territories and the District of Columbia) to match certain state expenditures for the medical care of low income persons who are age 65 or over, blind, disabled, or members of families with dependent children.71 Section 1901 of the Social Security Act explicitly states that the purpose of the Medicaid program is to enable each state to furnish medical assistance "and rehabilitation and other services... to help attain or retain capability for independence or self-care."

The Medicaid program is financed jointly by the federal and state governments, and is administered by the states. To qualify for federal funding, which is referred to as "Federal Financial Participation" (FFP), a state program must satisfy all applicable federal regulatory requirements on program policies.72 The regulations address such issues related to medical rehabilitation financing as whether a state must make certain categories of disabled people eligible for state Medicaid benefits, and which medical rehabilitation services a state must cover. To receive FFP, each state must develop its own Medicaid plan in accordance with the federal regulations, and operate its program according to the plan.

Table I indicates that the Medicaid program contributes approximately 16 percent of the inpatient revenues of rehabilitation hospitals, 14

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68 Provisions on coverage for home physical therapy are set forth at 42 C.F.R. Section 405.231(1)(2).

69 Coverage for durable medical equipment and prosthetic devices are set forth at 42 C.F.R. Sections 405.231(g) and (h), respectively.

70 42 U.S.C. Sections 1900 _et_ _seq._

71 In addition, clause (II) following Section 1902(a)(10)(E) of the Act allows a state to meet part or all of the Medicare deductibles, cost-sharing, and other charges for Medicaid recipients enrolled under Medicare Part B without obligating itself to provide those benefits or the range of Part B services to other recipients. Under Section 1903(a)(1), states are entitled to federal matching funds for payment of Medicare Part B premiums and deductibles for certain recipients. 42 C.F.R. Section 431.625.

72 42 C.F.R. Part 435, Sub-part K. The basic requirements for a state plan are contained in Section 1902 of the Social Security Act.

percent of the inpatient revenues of rehabilitation units, and 23.5 percent of inpatient revenues for other rehabilitation services. The actual percentages vary from state to state. The extent to which each state covers and reimburses optional medical rehabilitation services, and the number of rehabilitation patients eligible for Medicaid in a state, depend on the provisions of the state's Medicaid plan.

1) Eligibility for Medicaid benefits

The federal rules on Medicaid eligibility are set forth at length in 42 C.F.R. Part 435, and are extremely complex.[73] Basically, to qualify for FFP, state Medicaid programs must make eligible:

- all persons who receive cash assistance (or would receive such assistance if not for certain specified conditions) under the AFDC Program;[74]
- all persons who receive mandatory state cash supplements under the federal Supplemental Security Income (SSI) program, Title XVI of the Social Security Act;[75]

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[73] Due to the complexity of eligibility policy, the following discussion addresses only general provisions regarding the largest categories of persons who must be made Medicaid eligible and those who may be made Medicaid eligible. The reader should refer to the applicable HCFA regulations and manual provisions to understand the specific requirements.

[74] 42 C.F.R. Sections 435.110 through 435.115 (the federal program of Aid to Families with Dependent Children under Title IV-A of the Act).

[75] 42 C.F.R. Section 435.130. In the Social Security Amendments of 1972, Pub. L. 92-603, Congress established the SSI program as Title XVI of the Social Security Act to provide a uniform, nationwide cash benefit to low-income people who were aged, blind, or disabled. Prior to that time, there were four separate federal-assisted, state-administered programs of cash assistance under the Social Security Act:

1) Title I, Old Age Assistance;
2) Title X, Aid to the Blind;
3) Title XIV, Aid to the Permanently and Totally Disabled; and
4) Title IV-A, Aid to Families With Dependent Children.

States were required to make all recipients of cash assistance under these programs eligible for Medicaid.

The 1972 Social Security legislation consolidated the programs for the aged, blind, and disabled into a single SSI program. States that had made higher cash payments under their previous programs are required to make supplemental payments to the recipients of the difference between the SSI payment and the previous payment, and to make such recipients eligible for Medicaid. 42 C.F.R. Section 435.1.

- certain specified groups of persons who were eligible for Medicaid in 1973 (when the SSI program was established in law);76 and
- all persons in one of the two following categories:
  - a) all aged, blind, and disabled SSI cash recipients77; or
  - b) all aged, blind, and disabled persons who meet state eligibility standards more restrictive than those for SSI.78

The members of these groups of eligible individuals constitute the mandatory "categorically needy" population, and are entitled under federal law to certain Medicaid benefits.79

States may also grant Medicaid eligibility to certain members of the aged, blind, and disabled populations who do not receive cash assistance, but whose incomes and resources are insufficient to pay for necessary medical care.80 A state may choose among several federally defined categories of these persons for eligibility, and the members of the groups made eligible constitute the state's "medically needy" population. Even if a state makes eligible the members of a medically needy group, it may deny the members of that group coverage for some services that are mandated for the categorically needy population. If the state covers a particular service for members of a group of medically needy persons; however, it generally must make available the same amount, duration, and scope of that services to all members of

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[76] 42 C.F.R. Sections 435.122 through 435.133.

[77] 42 C.F.R. Section 435.120. The eligibility criteria for SSI are contained in 20 C.F.R. Part 416.

[78] 42 C.F.R. Section 435.121. The state standards can be no more restrictive than the state's Medicaid plan in effect in 1972 (when the SSI program was enacted).

[79] Under Section 1902(a)(10)(A)(ii), states may make eligible certain specified "optional categorically needy" groups of individuals who would qualify as mandatory categorically needy if not for their institutional status, enrollment in an HMO, receipt of home and community-based services, receipt of state supplemental payments, and other specified circumstances. 42 C.F.R. Sections 435.210, 435.211 and 435.212. Generally, if a state covers an optional categorically needy group, it must cover all eligible individuals in that group. 42 C.F.R. Section 435.201.

[80] 42 C.F.R. Part 435, Sub-part D.

the group.81

Fifteen states or territories have Medicaid plans that make eligible only members of the "categorically needy" population (HCFA, 1988). In most states, individuals who qualify for SSI payments are eligible for Medicaid as categorically needy persons.82 Fourteen states, however, exercise the option under Section 1902(f) of the Social Security Act to be more restrictive in defining disability and financial eligibility standards than SSI for purposes of determining Medicaid eligibility.83 In states that use the SSI standards, some blind and disabled Medicaid recipients who have previously received SSI, but who are no longer eligible for cash benefits because of an increase in earnings, may now retain Medicaid eligibility under Section 1619 of the Social Security Act.84

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81 42 C.F.R. Section 440.240(b)(2).

82 Provisions for the mandatory coverage of the aged, blind, and disabled are contained in 42 C.F.R. Sections 435.120 through 435.135.

83 This is often referred to as the "Section 209(b) option" because it was established in Section 209(b) of Pub. L. 92-603. The federal regulations on this option are contained in 42 C.R.F. Section 435.121.

84 Section 1619 was initially enacted as part of the Social Security Amendments of 1980 (Pub. L. 96-265), and was in effect from January 1981 through December 1983. Its purpose was to counter the disincentive for disabled recipients to work which results from the potential loss of Medicaid eligibility due to increased income.

In order to qualify under Section 1619, the recipient must:

1) continue to meet the SSI medical criteria for disability or blindness;

2) continue to meet all other SSI standards except for earned income;

3) be seriously inhibited from continuing employment if Medicaid eligibility would be lost; and

4) have insufficient earnings to provide a reasonable equivalent of SSI benefits and Medicaid.

The Secretary of DHHS extended the application of the Section 1619 provisions from January to December 1984 through a demonstration project. The Social Security Disability Reform Amendments of 1984 (Pub. L. 98-460) again extended the provisions through June 30, 1987. This authority was made permanent by Congress in Section 9404 of Pub. L. 99-509, OBRA of 1986, as well as in Pub. L. 99-643, The Employment Opportunities for Disabled Americans Act.

Most Medicaid recipients who receive comprehensive medical rehabilitation services are eligible for Medicaid as a result of qualifying for cash assistance under SSI.85 To receive SSI payments, an individual must be over age 65, legally blind, or disabled, and have a countable income86 of less than $4,248 per year and countable resources87 less than $1,900 (as of January 1, 1988).88 The definition of disability under SSI is identical to that used by the SSDI program.89 Thus, only persons with the most serious disabilities are eligible for SSI cash benefits. Children under 18 who are blind or disabled are eligible for reduced cash benefits.

Unlike SSDI beneficiaries who must wait two years to become eligible for Medicare, SSI recipients face no waiting period for Medicaid eligibility. Several factors, however, deter the disabled individual applying for SSI and Medicaid from receiving timely rehabilitation. These include the lengthy application process for SSI and Medicaid (including the need to show severe, long-term disability in order to qualify for SSI cash assistance), and SSI limitations on available financial resources resulting in the need to exhaust resources through medical expenditures before becoming eligible for benefits.

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85 42 U.S.C. Sections 1600 et seq.

86 Not all income of a recipient is counted toward the income eligibility limit. For example, each month $20 of a recipient's income is excluded, and $65 of earned income (i.e., wages and net earnings from self-employment) plus half of earned income above $65 are disregarded for purposes of determining income eligibility. There are also special exclusions from income for certain impairment-related work expenses.

87 Similarly, not all of a recipient's assets are counted toward the resource eligibility limit. Household goods and personal effects not exceeding $2000 in value, automobiles modified for persons with disabilities (and other automobiles that meet program criteria), certain life insurance policies, and burial spaces are excluded from the determination of resource eligibility.

88 Married couples may have an income up to $6,384 per year and resources up to $2,850, whether one of the spouses is eligible for Medicaid, under Section 1611(a) of the Social Security Act.

89 An individual is considered disabled if he or she is "unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of 12 months."

2) Medicaid Coverage and Payment for Medical Rehabilitation

Under federal regulations, state Medicaid programs must cover the following services, if medically necessary, for all categorically needy persons:

- inpatient hospital services;
- outpatient hospital services;
- lab and x-ray services;
- services in a skilled nursing facility;
- early and periodic screening and diagnosis and treatment;
- family planing, physician, and home health services.[90]

Although HCFA's regulation on Medicaid inpatient care for categorically needy persons does not specifically refer to coverage of medical rehabilitation, its language is sufficiently broad to encompass all necessary inpatient rehabilitation services. Inpatient hospital services refer to all services that are:

1) ordinarily furnished in a hospital for the care of inpatients;

2) furnished under the direction of a physician; and

3) furnished in an institution that:

   a) is primarily for the care and treatment of patients with disorders other than mental diseases;

   b) is licensed or approved by the state;

   c) meets requirements for Medicare participation, and has in effect a utilization review plan.[91]

Rehabilitation provided in an acute care hospital or a rehabilitation hospital would generally satisfy this definition. HCFA's regulation requiring Medicaid outpatient care for the categorically needy population refers specifically to coverage of rehabilitation services.[92]

Most of the services a state must cover for persons who are categorically needy, however, do not have to be covered for those persons eligible as medically needy (except under limited circumstances). States generally are not mandated to cover inpatient or outpatient care in a hospital for their medically needy populations, although prenatal care, ambulatory services and home health services must be covered for medically needy individuals entitled to SNF services.93 Therefore, medically needy Medicaid recipients are not necessarily entitled to medical rehabilitation services in a hospital or SNF, unless the individual's state chooses to cover such services.

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[90] 42 C.F.R. Section 440.210.

[91] 42 C.F.R. Section 440.10.

[92] 42 C.F.R. Section 440.20.

For both their categorically needy and medically needy populations, states generally may choose whether to cover medical rehabilitation services in other (i.e., non-hospital) settings.94 For example, although Medicaid requires states to cover home health services for all categorically needy and some medically needy Medicaid recipients, states are not required to mandate that home health agencies offer physical therapy, occupational therapy, speech pathology, and audiology services.95

Conversely, although states are not required to cover care at a SNF or an ICF for their medically needy populations, if such care is covered, SNFs and ICFs must provide medical rehabilitation services to recipients as needed.96 Also, states are not required, but have an option, to cover rehabilitative "clinic services,"97 physical therapy,98 and prosthetic devices at other non-hospital settings.99

For all services covered, a state Medicaid plan must specify the amount, duration, and scope of the service covered (which must be

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93 42 C.F.R. Section 440.220.

94 Under 42 C.F.R. Section 440.130, "rehabilitative services" is defined as "any medical or remedial services recommended by a physician or other licensed practitioner of the healing arts, within the scope of his practice under State law, for maximum reduction of physical or mental disability and restoration of a recipient to his best possible functional level."

95 42 C.F.R. Sections 440.70(b) and (b)(4).

96 Under 42 C.F.R. Section 442.343, ICFs must either provide or arrange for the provision of rehabilitation services, as needed, by qualified therapists or assistants to maintain and improve the resident's ability to function independently, prevent advancement of progressive disabilities, and restore maximum function.

97 Clinic services are defined as preventive, diagnostic, therapeutic, rehabilitative, and palliative items or services provided to outpatients generally under the supervision of a physician by a facility that is not part of a hospital. 42 C.F.R. Section 440.90.

98 42 C.F.R. Section 440.110.

99 42 C.F.R. Section 440.120.

sufficient to reasonably achieve its purpose).100 It must also specify that the available amount, duration, and scope of each covered service is equal for all individuals in an eligibility group (i.e., the categorically needy or any covered medically needy group).101 A state Medicaid agency may not arbitrarily deny or reduce the amount, duration, or scope of a covered service to an eligible recipient solely because of diagnosis, type of illness, or condition, but may place appropriate limits on the service based on medical necessity, utilization review procedures, and similar criteria.102

A 1988 survey of state Medicaid policies by HCFA's Office of Intergovernmental Affairs summarized the optional coverage policies of the various state Medicaid plans (HCFA, 1988). In 1987, according to that survey, 35 states (or territories) covered physical therapy and 25 states covered occupational therapy under their Medicaid plans. Thirty-seven states covered other non-mandatory rehabilitation services under their Medicaid programs; 9 states covered such rehabilitation services only for the categorically needy population and 28 states covered such services for both the categorically needy and the medically needy populations (HCFA, 1988).103

States have considerable flexibility in setting payment policies for services provided under their Medicaid programs. Although states were at one time required to use the principles of cost-based reimbursement used by Medicare, they are no longer limited to that payment methodology. The basic requirement for payment of hospital, SNF, and ICF inpatient services is that the state Medicaid plan must set forth rates that are "reasonable and adequate to meet the costs that must be incurred by efficiently and economically operated facilities to provide services in conformity with state and federal laws, regulations, and quality and safety standards."104

In addition to providing assurances satisfactory to HCFA that inpatient rates are "reasonable and adequate" for efficiency, each state plan must make the following additional assurances:

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100 42 C.F.R. Section 440.230.

101 42 C.F.R. Section 440.240.

102 42 C.F.R. Section 440.230(c) and (d).

103 Since 1987, some states may have altered their Medicaid rehabilitation policies regarding optional rehabilitation services.

104 See 42 C.F.R. Part 447 Sub-part C, which implements Section 1902(a)(13)(A) of the Act.

1) that the methods and standards used in determining rates take into consideration the situation of hospitals that serve a disproportionate share of low income patients with special needs;

2) that the rates are adequate to assure that recipients have reasonable geographic access to quality inpatient hospital services; and

3) that the payment rates are reasonably expected to pay no more in the aggregate for inpatient hospital services or long-term care services than would be paid under the Medicare principles of reimbursement.105

Similar to the program requirements for payment of inpatient care, state payments for outpatient services under Medicaid must be consistent with efficiency, economy, and quality care. Under federal regulations, a state Medicaid agency may pay the customary charges of a provider for outpatient care, but may not pay more than the prevailing charges in the locality for comparable services.106

Most states still reimburse rehabilitation hospitals and units on a retrospective cost basis, subject to prescribed ceilings. Several states have initiated prospective payment systems for payment of inpatient hospital care under their Medicaid programs. Although freestanding rehabilitation hospitals are often exempt from payment under these systems (as under Medicare's PPS), rehabilitation units in acute care hospitals are often included. States that have prospective payment systems for rehabilitation units are now attempting to monitor the cost experience of these units under the new systems.

C. Veterans Administration

The Veterans Administration (VA) finances the medical care of millions of people through its provision of health care services to eligible veterans (and, under some circumstances, to members of their families). The VA's Rehabilitation Medicine Service provides rehabilitative care at all 172 VA Medical Centers and most of its 229 outpatient clinics and 117 nursing homes. In 1986, there were 1,336 hospital beds designated for medical rehabilitation at 60 VA medical centers, as well as five comprehensive rehabilitation centers (VA, 1987).107 In that year, the VA Spinal Cord Injury Service, which addresses the needs of over 15,000 quadriplegics and 11,000 paraplegics, treated 7,705 inpatients and 12,948 outpatients and provided 25,516 home visits (VA, 1987).

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105 42 C.F.R. Section 447.253.

106 42 C.F.R. Section 447.325, which, in part, implements Section 1902(a)(30) of the Act.

107 The five VA rehabilitation centers are located in Boston, MA; Newport, NY; Tampa, FL; Hines, IL; and Palo Alto, CA.

Although the VA provides rehabilitation and other medical services directly through its broad network of health care facilities, it recently has implemented a DRG-based system to help determine the appropriate allocation of medical resources throughout its system. Since DRGs were constructed for short-term acute care and do not adequately reflect lengths of stay or resource utilization in rehabilitation, there is concern that this will result in inadequate budgets for rehabilitation services in the VA. Some analysts argue that either the VA's DRGs must be modified to reflect true case-mix and resource utilization, or rehabilitation should be exempt from the VA allocation system (DeLisa, 1985).

1) Eligibility for VA Benefits

The Consolidated Omnibus Budget Reconciliation Act of 1985 revised the eligibility criteria for receiving inpatient care at a VA hospital.108 Generally, the law is designed to ensure that veterans with service-connected disabilities and certain other specified categories of veterans receive hospital care and other health care services when necessary. It also establishes a "means test" for the eligibility of other veterans who have very limited financial resources. The eligibility criteria define three categories of veterans who may be eligible for health care benefits: Category A, B, and C veterans.

Category A veterans, who are given first priority in receiving needed medical care, include veterans with service-connected conditions, as well as veterans:

- who are former prisoners of war;
- who were exposed to herbicides while serving in Vietnam and need treatment for conditions possibly related to exposure;
- who were exposed to ionizing radiation and need treatment for conditions that might be related to exposure;
- who served in the Spanish-American War, the Mexican border period, or World War I;
- who are eligible for Medicaid;
- who are disabled due to non-service-connected circumstances, but who meet other criteria specified in law; or

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108 Section 19011(a) of Pub. L. 99-272. See Title 38 United States Code, Section 610.

- who have non-service-connected conditions, and who receive VA pensions and have incomes less than that specified in the law.109

Veterans who do not qualify under Category A may still receive care under Categories B or C at a VA medical facility on a "space available" basis. Category B comprises veterans with non-service-connected conditions who have incomes that are too high to qualify under Category A, but are within other limits set by law.110 Category C includes veterans with non-service-connected conditions with incomes too high to qualify under Category B. Unlike Category A and B veterans, Category C veterans are subject to deductibles and copayments for any inpatient or outpatient care under the VA system.

Health care benefits are also available to the spouses and dependents of veterans under some circumstances. The Civilian Health and Medical Program of the Veterans Administration (CHAMPVA) provides medical care for:

1) the spouse of a veteran who died as a result of a service-related injury; or

2) the spouse or child of a veteran with a total and permanent service-connected disability who had such a disability at time of death or who died while on active duty.

In addition, the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS), administered by the Defense Department, provides health insurance for military retirees and their dependents.

2) VA Coverage and Payment for Medical Rehabilitation

Under the VA system, virtually all types of inpatient and outpatient care, including medical rehabilitation services, are covered for eligible veterans. VA physicians make the ultimate determination as to

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109 In 1988, a single veteran with a non-service-connected condition who receives a VA pension could have an income of no more than $15,833, and a married veteran (or a veteran with dependents) with a non-service-connected condition who receives a VA pension could have an income of no more than $18,999 (plus $1,055 per dependent), to be eligible under Category A.

110 In 1988, a single veteran with a non-service-connected condition could have an income between $15,833 and $21,110, and a married veteran (or a veteran with a dependent) with a non-service-connected condition could have an income between $18,999 and $26,388 (plus $1,055 per dependent), to be eligible under Category B. These income amounts, as well as those applicable to Category A eligibility, are adjusted January 1 of each year by the same percent that VA pension rates are increased.

whether inpatient care is warranted in each case. Services are usually administered at a VA health care facility. If a particular facility is fully occupied, priority is given to veterans according to their VA priority group (i.e., Category A, B, or C), irrespective of severity of illness or disability (except in the case of emergencies). Occasionally, when warranted by special circumstances, the VA authorizes payment for hospital care at a non-VA facility.

The VA now focuses its rehabilitation services largely on an outpatient basis. Veterans may receive outpatient care for any condition if they:

1) are at least 50 percent disabled by a service-connected disability;

2) receive VA aid, attendant services, or housebound benefits;

3) were prisoners of war; or

4) were in World War I.

Veterans who do not meet any of these criteria also may receive outpatient rehabilitation and other outpatient care, as needed, according to service availability and based on the VA's priority groups. As part of outpatient medical treatment, disabled veterans may be eligible for home health services to effectively and economically address their needs. In addition to medical services, these include home improvements and structural alterations.

Other rehabilitation-related benefits available to eligible veterans are the provision and repair of prosthetic appliances, such as artificial limbs, braçes, hearing aids, augmentative communication devices, mechanical wheelchairs, and electric wheelchairs (VA, 1986). The VA Prosthetic and Sensory Aids Service (PSAS) provides devices and services through a network of Prosthetic Treatment Centers, Amputee Clinic Teams, Prosthetic/Orthotic Laboratories, Restorations Clinics, and Special Teams for Amputation, Mobility, Prosthetics/Orthotics (STAMPS). In FY 1986, PSAS provided services costing $97 million to over a million disabled veterans (including 10,778 artificial limbs for $17 million and 28,683 wheelchairs for $1 million).

For coverage of equipment, a VA representative must authorize the appliance for the individual. This determination is based upon several factors including specific VA guidelines for each type of appliance, whether similar items were previously issued for the individual, and the individual's need for the requested item in relation to his or her condition. Most appliances are subject to prescribed cost limitations.

D. Vocational Rehabilitation Agencies

Another source of funding for medical rehabilitation services is state-administered vocational rehabilitation agencies. The programs of such agencies are financed, in part, with federal funds under Title I of the Rehabilitation Act of 1973, as amended. The primary purpose of vocational rehabilitation agencies is to enhance the employability of disabled persons. Like the Medicaid program, states may receive FFP for providing services pursuant to a state plan in accordance with federal regulations. Among such regulations are provisions setting forth eligibility requirements and mandating that services be provided pursuant to an individualized written rehabilitation program (IWRP) for each rehabilitation "client".111

Eligibility for vocational rehabilitation benefits is based upon:

- the presence of a physical or mental disability which constitutes or results in a substantial handicap to employment for the individual; and

- a reasonable expectation that vocational rehabilitation services may benefit the individual in terms of employability.112

Based on these standards, an appropriate member of the state vocational rehabilitation agency must certify an individual's eligibility or ineligibility for benefits.113 Although there are no federal requirements that the financial need of the individual be a criterion for eligibility or required contributions to benefits, states may impose such requirements for their programs.114

Vocational rehabilitation agencies must, at a minimum, provide evaluations of rehabilitation potential, including diagnostic and related services; counseling, guidance, referral, and placement services; and vocational and other training services to enhance the employability of eligible individuals.115 They also must provide a variety of other services, including "physical and mental restoration" services, if "comparable services and benefits are not available under any other program."116 "Restoration" is defined to include a broad range of

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111 34 C.F.R. Section 361.40.

112 34 C.F.R. Section 361.31(b). Under Section 361.31(c), a state may immediately, upon request, begin to provide vocational rehabilitation services based on an initial determination of eligibility, but must make a final determination within 90 days of the initial determination. The final determination of eligibility must be based on a full evaluation of vocational rehabilitation potential, including a diagnosis pertaining to the individual's health. 34 C.F.R. Sections 361.32 and 361.33.

113 34 C.F.R. Section 361.35.

114 34 C.F.R. Section 361.47.

115 Section 103 of the Rehabilitation Act.

116 Section 101(a)(8) of the Rehabilitation Act.

medical and health care services, including medical rehabilitation services, for the rehabilitation client.117

In determining whether to provide restorative services to a client, the state agency must give full consideration to all comparable benefits available to an individual to meet the costs of physical and mental restoration services (e.g., Medicaid, Medicare, or private insurance), unless it would significantly delay services to the individual.118 Therefore, vocational rehabilitation generally serves as a payor of last resort for restoration services. In 1985, $148,000,000 (representing 21.6 percent of the total $684 million vocational rehabilitation budget for services to individuals) were spent by vocational rehabilitation agencies under the general category "physical and mental restoration services" (RSA, 1986). An additional $126,000,000 (or 18.4 percent of the "services for individuals" budget) was spent on diagnoses and evaluations relating to assessment of functional capacity (RSA, 1986).

A breakdown of the broad category of "restoration" expenditures into its component parts for the entire nation currently is not available. It is, therefore, uncertain what percentage of restoration provided by vocational rehabilitation agencies in each state constitutes payment for medical rehabilitation services, as opposed to other medical and health care services. It appears, however, that medical rehabilitation services constitute the largest component of "restoration expenditures." For example, the New York State Office of Vocational Rehabilitation expended approximately 70 percent of its $788,449 FY 1986 "restoration expenses" budget on prosthetics, orthotics and adaptive devices, wheelchairs, speech therapy, hearing therapy, language therapy, physical therapy, and occupational therapy.119

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117 These include medical or corrective surgical treatment, diagnosis and treatment of mental or emotional disorders, dentistry, nursing services, necessary hospitalization, convalescent or nursing home care, drugs and supplies, *prosthetic, orthotic or other assistive devices,* eyeglasses, podiatry, *physical therapy, occupational therapy, speech or hearing therapy, psychological services, therapeutic recreation services, social work,* treatment of acute or chronic medical complications, services for treatment of end-stage renal disease, and "*other medical or medically-related rehabilitation services*". (Emphasis added). 46 *Federal Register* 5525 (Vol. 46, no. 12, Monday, January 19, 1981).

118 34 C.F.R. Sections 361.47(b)(2) and (3).

119 In total, $556,110 was spent by New York OVR in FY 1986 for such rehabilitation services (including support services associated with the primary rehabilitation service); $126,336 for prosthetics, $39,929 for orthotics and adaptive devices, $164,798 for wheelchairs, $76,696 for hearing, speech or language pathology, and $148,421 for physical or occupational therapy. These unpublished statistics were provided by the State of New York.

E. Analysis of Public Sector Payors

The major public sector payors of medical rehabilitation -- HCFA, state Medicaid agencies, the Veterans Administration, and state vocational rehabilitation agencies -- have played an essential role in financing medical rehabilitation services in this country. They pay for the majority of rehabilitative care, and have been the leaders in developing rehabilitation financing policy. From the 1960s until recently, the public sector programs have served to expand significantly the availability of medical rehabilitation services to the population.

It is, however, important to recognize that the public sector programs were designed primarily to serve as payors for certain "protected" groups (i.e., Medicare for aged, blind, and disabled persons; VA health benefits for eligible veterans; and Medicaid for indigent persons and families). Consequently, certain disabled persons who require medical rehabilitation services, but who do not meet the formal eligibility requirements of these programs (and who have no other means of payment through private health insurance or extensive personal resources), are "falling between the cracks" of the health insurance and medical rehabilitation systems. This is true at least until they exhaust almost all their financial resources and thereby qualify for Medicaid.

In addition, the coverage packages of the public sector programs are often inadequate to meet fully the needs of the disabled population. Medicare does not cover the long-term "extended care" rehabilitation services needed by many disabled persons. State Medicaid and vocational rehabilitation agencies vary considerably with respect to the types and amounts of medical rehabilitation covered, although many cover only the minimum required by law. Vocational rehabilitation agencies have a primary responsibility to provide "vocational" services, and most cover medical rehabilitation only as a last resort. The Veterans Administration provides rehabilitation services based upon the VA's categorical priorities and service availability, and does not always have adequate capacity to meet all rehabilitation needs.

For the rehabilitation services that are covered, Medicare's eligibility rules and the restrictive payment policies used by many public sector payors may discourage the timely provision of rehabilitative care. This is likely to compromise optimal rehabilitation outcomes. Further, as a result of increases in the number of disabled persons requiring medical rehabilitation, and fiscal austerity measures by Congress and the present Administration, the public sector programs are proving increasingly inadequate to meet fully the rehabilitation needs of disabled persons who do not have other sources of payment. Thus, there is a need to reexamine carefully the eligibility, coverage, and payment policies of the major public sector payors. This examination will require substantial research on the rehabilitation needs (and other health care needs) of the disabled population, and the extent to which the public sector programs are meeting their needs.

It is also necessary to investigate more fully the private sector as a source of payment for medical rehabilitation services. Increasingly, the public sector is looking to the private sector as a resource to implement public policy. Through a variety of approaches, including the imposition of mandated benefits and the contracting with private providers for services, the federal, state, and local governments have attempted to use their authority and financial leverage to provide affordable, high quality health care services to the population. Part III of this monograph considers the private sector payors of medical rehabilitation and their rehabilitation financing policies.

III. PRIVATE SECTOR PAYORS OF MEDICAL REHABILITATION

Although the private sector finances less of the medical rehabilitation bill than does the public sector, it is playing an important and rapidly growing role in the financing of medical rehabilitation services. Among the payors of rehabilitation in the private sector are health insurers, disability insurers, health maintenance organizations (HMOs) and other prepaid managed care providers, self-insured employers, and casualty insurers. This part of the monograph considers the enrollment,[120] coverage, and payment policies of these payors as they relate to medical rehabilitation services.

Part II considered a relatively small number of public sector payors required by law to publish their policies for broad public review and scrutiny. This part of the monograph addresses a much larger number of private sector entities. Most do not set forth explicitly in publications all aspects of their rehabilitation financing policies. Many have a variety of different enrollment, coverage, and payment policies for different group and individual plans. Due to the enormous diversity of separately negotiated insurance policies, it is not possible to draw definitive "across-the-board" conclusions on the rehabilitation financing policies of the private sector.

The following sections provide a summary of the rehabilitation financing policies used by the various categories of private sector payors. The conclusions are based on a review of a select number of insurance policies and the representations of numerous insurance and rehabilitation professionals. They are not necessarily true of all contracts issued by, or policies of, the various companies. Rather, the following sections provide a general overview of the rehabilitation financing approaches developed by private sector payors, and the incentives to which the private sector payors respond.

A. Background on Private Sector Payors

There are two general types of insurance in the private sector. They are:

1) life, health, and disability insurance (including HMOs and other prepaid managed care plans that constitute a growing form of health insurance), which provide coverage for the insured individual and typically the individual's nuclear family; and

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[120] The concept of "enrollment" in the private sector is somewhat analogous to "eligibility" in the public sector, although the public sector payors tend to have much more elaborate rules as to whether an individual may receive benefits under the program. The private sector generally has much more discretion in accepting or rejecting an individual for individual policies (though very little discretion under group policies).

2) property and casualty insurance (including workers' compensation, automobile liability, automobile no-fault, personal liability, and general liability), which provides coverage for injuries to individuals other than the insured.

With the exceptions of life insurance and property insurance (which typically do not cover the costs of disability), these types of private sector insurance have played a substantial role in paying for medical rehabilitation services.121 Private sector insurers, including Blue Cross/Blue Shield, HMOs, PPOs, PPAs, workers' compensation plans and other "commercial insurance," in the aggregate, account for approximately 30 percent of all inpatient rehabilitation hospital revenues (Sonik, 1988).122

Historically, the various payors in the private sector have addressed issues of medical rehabilitation financing in a variety of ways. Some insurance companies have paid for medical rehabilitation services for over half a century; a few still do not cover rehabilitation. Casualty insurers provided the initial leadership in expanding access to medical rehabilitation services. As early as 1913, the Liberty Mutual Insurance Company established the first rehabilitation hospital owned and operated by an insurance company (England, 1986). Similarly, in 1922, Aetna Life and Casualty opened a rehabilitation center in Syracuse, N.Y. Other insurers, including health and disability insurers, have gradually over time begun to pay for, and increase coverage of, medical rehabilitation services.

Many private sector payors still do not, as a matter of policy, cover the full scope of medical rehabilitation services. Many address rehabilitation coverage only informally on an ad hoc, extra-contractual basis. The failure of such payors to cover medical rehabilitation services formally has been attributed to a lack of understanding of the rehabilitative process by the insurance industry, and a belief by some payors that coverage of rehabilitation would not be cost-beneficial (Rusk, 1978; Mittelmann, 1980; England, 1986). The term "cost-beneficial" is used narrowly here to mean that the costs of medical rehabilitation services are justified by the savings realized by the insurer. It must be recognized that, even if rehabilitation is not deemed cost-beneficial from the insurer's narrow financial perspective, it still may be considered very cost-beneficial from the broader perspectives of the patient and society.

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121 Because life insurance and property insurance generally do not cover medical rehabilitation, they are not discussed further in this monograph. Some life and property insurance policies do have health, disability and/or casualty insurance "riders" that may cover some rehabilitation services.

122 This figure is based on the results of the 1986 AHA Survey. The survey's category of "commercial insurance" does not provide specific insight on the percentage of revenues derived from each of the separate insurance categories: health, disability, and casualty insurance.

Recently, the medical rehabilitation community has been more successful at communicating the benefits of rehabilitation to insurers and the public. More studies than ever before are documenting the cost-benefits and cost-effectiveness of medical rehabilitation (Eazell and Johnson, 1981; Johnson and Keith, 1983; HIAA, 1987).[123] Consequently, the rehabilitation industry now is seeing the signs of more private sector organizations covering medical rehabilitation services and programs. In addition, many payors are becoming more actively involved in the comprehensive coordination of rehabilitation and other services needed by their enrollees (Mittelmann, 1984; Knable, 1986).

Some payors now employ as case managers registered nurses and rehabilitation counselors to develop or coordinate comprehensive rehabilitation plans for disabled enrollees. Others have established separate rehabilitation divisions for their organizations. Still others rely on private rehabilitation contractor firms to manage their rehabilitation cases. The wide variety of approaches being developed to address the rehabilitation needs of disabled enrollees suggests that the general concept of disability case management is rapidly growing (NARF, 1982; Ohio Self-Insurers, 1982; England, Amkraut, and Lesparre, 1986; Carbine and Schwartz, 1987). This is further evidenced by the increasing number of case management firms emerging to service this market (Carbine and Schwartz, 1987).

Thus, payors in private sector employ a broad variety of medical rehabilitation financing policies, ranging from no medical rehabilitation coverage to full coverage of all medical rehabilitation services with comprehensive case management. In describing and analyzing the private sector payors of rehabilitation, it is important to recognize that the various payors, such as health insurers, disability insurers, HMOs, and casualty insurers, have different obligations and different incentives to cover medical rehabilitation services. These obligations and incentives, and the financing policies that the payors have adopted in response to them, are discussed at length in the sections below.

B. Health and Disability Insurance

Of the two general types of private sector insurance discussed above, health and disability insurance now pay the largest percentage of medical rehabilitation costs. Health insurance pays for medical rehabilitation services to the extent that such services are covered under the insurance contract between the insurer and the insured. Coverage under the health insurance contract, in turn, is determined (in the case of group insurance plans) by the contract negotiations between the insurer and the representative of the insured, and (in the case of individual plans) by the unilateral policy decisions of insurers. The insurer's policy decisions and negotiation positions are based, in large part, on actuarial determinations of the costs and risks of the population (Mittelmann, 1984).

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[123] There is still a real need to conduct more cost-benefit analyses and cost-effectiveness analyses to document whether particular medical rehabilitation services are economically justified. Most studies conducted thus far have had problems with research methodology, including statistical technique and sample selection (Johnson and Keith, 1983).

Disability insurance compensates insured workers and their families for lost income resulting from a disability that prevents the worker from engaging in the occupation held at the onset of the disability. Like health insurance, coverage under disability insurance is dictated by the provisions of the contract between the insurer and the insured. Unlike health insurance, disability insurance contracts typically do not formally cover the costs of medical care, such as medical rehabilitation. Despite this, some long-term disability insurance plans have paid for medical rehabilitation services on an ad hoc, extra-contractual basis in order to return the enrollee to work as soon as possible.

More than 800 private insurance companies write medical expense or disability income policies in this country (HIAA, 1986). Although the policies of health and disability insurers vary from company to company and from contract to contract, several general approaches to rehabilitation financing can be discerned from these two categories of insurers. These approaches are described in the following sections.

1) Health Insurance

Although there are no good national statistics on the percentage of medical rehabilitation services paid by private health insurers generally, Blue Cross/Blue Shield alone accounts for approximately 11 percent of rehabilitation hospital inpatient revenues and 10 percent of rehabilitation unit inpatient revenues (Sonik, 1988). HMOs, PPOs, and preferred provider arrangements (PPAs) account for another 0.5 to 1 percent of rehabilitation revenues (Sonik, 1988)[124] Other private health insurers contribute a majority of the 16 percent of gross inpatient revenues for rehabilitation hospitals and the 11 percent of gross inpatient revenues for rehabilitation units paid by "commercial insurance" (Sonik, 1988). *See* Tables I and II.

The two types of health insurance most relevant to the financing of medical rehabilitation are (1) primary hospitalization and (2) major medical insurance.[125] Primary hospitalization pays the cost of covered hospital bed and ancillary services up to prescribed limits. In cases that require extended acute hospital stays, such as spinal cord injury and head injury, hospitalization insurance often is exhausted by the time the individual is medically stable enough to start rehabilitation. Major medical insurance, which provides broad and substantial coverage for large, unpredictable medical expenses, then pays for the remainder of covered services (up to prescribed ceiling, if any) (Mittelmann, 1984).

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[124] HMOs, PPOs, and PPAs are all grouped together in a single category in the *AHA Survey*, despite the fact that they are very different types of organizations or arrangements. These organizations are described later in Part III.

[125] Health insurers offer a wide variety of policies that provide a combination of hospitalization and major medical benefits; however, most policies can be characterized according to these two components.

Due to the high costs of trauma care, post-trauma acute care, and medical rehabilitative care,126 a health insurance policy that does not include a substantial major medical component for catastrophic illness or injury is not likely to provide adequate coverage for comprehensive medical rehabilitation services or extended rehabilitation services (NARF 1983; NHIF, 1988).127 Therefore, the prevalence of major medical insurance, to the extent that such policies cover medical rehabilitation, is particularly relevant in considering the financing of rehabilitation services. The benefits of such policies may range from $10,000 per person to an unlimited amount (HIAA, 1986).

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126 Recent data indicate that the average charge for a patient at a rehabilitation hospital alone (not including prior trauma care or acute care) is $17,456 (Sonik, 1988).

127 The National Head Injury Foundation cites an example, for purposes of illustration, of the health-related costs of a person with a severe head injury (NHIF, 1988). The costs are as follows:

I. Acute Medical Care

A. Average Length of Stay = 60 to 90 days
B. Average Cost Per Diem = $2,000
C. Total (75 x $2,000) = $150,000

II. Acute Rehabilitation Costs

A. Average Length of Stay = 90 to 120 days
B. Average Cost Per Diem = $550 - $600
C. Total (105 x $575) = $60,365

III. Extended Rehabilitation

A. Average Length of Stay = 15 months
B. Average Cost Per Month = $13,000
C. Total (15 x $13,000) = $195,000

IV. Residential Program for Remainder of Life
(Average Age of Person = 15 to 25 years)

A. Average Length = 30 to 60 years
B. Average Cost Per Year = $60,000 - $125,000
C. Total (45 x $92,500) = $4,162,500

Total of All Lifetime Care = $4,567,875

a) Enrollment in health insurance

Studies vary substantially in their estimates of the uninsured population in this country. Most studies estimate that between 30 and 35 million persons under age 65 have no public or private coverage (Sulvetta and Schwartz, 1986). According to a study by The Urban Institute, 32.7 million people, constituting 16 percent of population under 65, were uninsured in 1982 (The Urban Institute, 1984).

Another study indicated that, at the end of 1983, more than 192 million Americans, constituting 82 percent of the civilian, non-institutional population (and 86 percent of persons under age 65) had one or more forms of health insurance (HIAA, 1986). Nearly 90 percent of surveyed employees in 1980 had a major medical policy, and 73 percent had maximum benefits of $250,000 or more. In 1984, major medical coverage increased to 93 percent of surveyed employees (HIAA, 1986).

Although these figures vary considerably, and the most optimistic statistics suggest that most people are insured for the catastrophic costs of rehabilitation, they do not tell the entire story. This is, in part, because 61 percent of the population is covered through the current employment of family members, and therefore coverage may be lost if employment terminates (U.S. Department of Commerce, 1983). Congress and the states are seeking new ways, including the development of "risk pools" and "Medicaid wraparound plans," by which the uninsured population can gain access to affordable health insurance (IHPP, 1988).

b) Coverage and payment by health insurance

Coverage and payment of health insurance benefits is defined primarily by the contract between the insurer and the insured, subject to the contract law and insurance regulations of the state in which the policy is issued. Traditional health insurance plans specify in their enrollee contracts (or in an accompanying pamphlet referenced in the contract) the services and providers they cover. Generally, such plans either reimburse the enrollee, or reimburse providers directly on behalf of the enrollee, for the "usual, customary, and reasonable" charges for covered health care services. Blue Cross/Blue Shield plans, for example, provide benefits to enrollees through separate contracts with member hospitals, and generally reimburse the provider directly for covered services.

There has been little research on the underwriting practices used by health insurers to determine coverage of services, such as medical rehabilitation, needed by the disabled population. Many insurers rely very heavily on the "Society of Actuaries Medical Impairment Study" for determining the risk classifications and consequent premiums for persons with disabilities (Thompson, 1988). The Medical Impairment Study has been broadly criticized for not being updated frequently enough and for having certain methodological problems (Thompson, 1988). Consequently, health insurers often have difficulty in accurately assessing the health risks of different disabled populations.

Insurers claiming to be unable to obtain current, consistent, and reliable loss experience for disabled persons often rely on reinsurers (those insurance companies that insure other insurance companies) to assess the risks of these individuals. Reinsurers, which also typically do not have access to adequate disability data, must rely, to large extent, on the application of theoretical actuarial models to impute the experience of small disabled populations (Cowell and Haskins, 1987). The lack of good data on the costs of disabled persons has been used by some insurers as a justification for failing to insure such individuals. Clearly, there is a need for better cost data, specifically by each disability, on the health care utilization and costs of disabled persons. The lack of good data is particularly pertinent in considering the general lack of insurance coverage for the ongoing rehabilitation needs of persons who are currently disabled.

The actuarial task of estimating an individual's risk of requiring initial comprehensive medical rehabilitation services in a rehabilitation hospital or unit is somewhat less problematic. This actuarial task entails an estimation of the probability that a person in the general population (not a specific disabled population or populations) will become sufficiently physically disabled to require comprehensive rehabilitation in any given year. Such statistics are readily available from the state and federal governments, and are based on the experience of the overall population, not small statistically unreliable samples.

i. Health insurers generally

Despite the fact that good data is available on the risks of insureds requiring comprehensive medical rehabilitation, few health insurers have an explicitly stated policy for coverage and payment of comprehensive medical rehabilitation services. A recent survey by the Rehabilitation Subcommittee of the Health Insurance Association of America's Disability Insurance Committee indicates that only 70 of the 139 responding insurance companies had a rehabilitation program, and 49 of the 70 companies with programs covered rehabilitation only on an ad hoc, extra-contractural basis (HIAA, 1987). Even if an individual is fully insured with no catastrophic limits to his or her coverage, an insurer may choose not to pay for rehabilitation expenses if such services are not explicitly covered by the plan.

Although many companies do not have an explicitly stated rehabilitation coverage or payment policy, increasingly health insurers have been interpreting the terms "hospital care" (which is generally a covered service) in their coverage policies to include care provided at a rehabilitation hospital or unit. This has changed since the 1960s and 1970s, when a large percentage of the relatively few insurers that "officially" covered medical rehabilitation services did so only if such services were provided in a hospital with surgical facilities (HIAA, 1978). Through this "surgical facilities" requirement, insurers excluded coverage of services and programs offered in freestanding rehabilitation hospitals.

In 1978, the Health Insurance Association of America (HIAA), prompted by concerns raised by the National Association of Rehabilitation Facilities (NARF), issued a policy memorandum stating that:

1) As a general principle, individual companies should consider covering medical rehabilitation services rendered in a rehabilitation hospital when such services would be a covered benefit in acute-care general hospitals;

2) Insurance companies should recognize rehabilitative care as an exempted modality of treatment and an integral part of the health care delivery system;

3) Insurance companies must maintain flexibility to exclude or limit benefits and specify the level of services to be covered in order to serve policyholders, but such exclusions or limitation should be fair and reasonable;

4) The requirement that a surgical facility be present on the premises should not be overstated and should be limited to the purpose and scope of coverage desired by the policyholder. (HIAA, 1978).

Since the release of the 1978 HIAA memorandum, very few, if any, insurers still require that rehabilitation providers maintain surgical facilities to qualify for coverage. Some insurers still explicitly exclude rehabilitation services in their policies for other reasons. One important reason, raised to the HIAA by NARF, is that some insurers have policies that confuse medical rehabilitation with custodial care (which is typically not covered by insurance), and therefore explicitly exclude coverage of rehabilitation. In response to the criticism that skilled rehabilitative care is very different from custodial care, HIAA recently updated its 1978 memorandum, stating that:

1) Insurance companies should consider developing hospital definitions written to include all licensed facilities rendering hospital levels of skilled care.

2) Rehabilitative care is provided in a wide variety of settings and requires an intensity of skilled services that sets it apart from custodial care. As a result it should not be singled out for exclusion. (HIAA, 1988).

As a result of this important statement by HIAA, it is likely that an increasing number of health insurers will explicitly cover medical rehabilitation services in the coming decade.

Currently, it appears that the majority of health insurance companies still cover medical rehabilitation service only on an ad hoc, extra-contractural basis (HIAA, 1987). Although there is no firm contractual language in their policies that mandates the coverage of rehabilitation services, the companies may choose to cover such services as the need arises, if the rehabilitation is thought to be medically appropriate and financially justified.

The problem with this ad hoc approach is that it:

1) does not create a legal right to rehabilitation for enrollees who require the service;

2) leaves enormous discretion on the part of the claims managers of the insurance companies arbitrarily to deny needed rehabilitation; and

3) leaves enrollees uncertain as to the extent of their total insurance coverage.

ii. Health insurers that explicitly cover rehabilitation

There are several exceptions to the general situation in which insurers either explicitly exclude coverage of rehabilitation services or fail to explicitly include coverage of such services. First, a few companies have voluntarily included rehabilitation services in their stated contractual coverage. Second, insurers in states that mandate coverage of certain rehabilitation services through their insurance laws cover the full scope of rehabilitation services required by law. Third, contracts of insurers under the highly competitive Federal Employees Health Benefits Program (FEHBP) tend to be more generous than typical group or individual plans, and many explicitly cover at least short-term medical rehabilitation services. Finally, special contracting arrangements between insurers and providers of rehabilitation, called preferred provider arrangements, are now being developed.

a. State law

In many states, private insurance companies are required to offer certain minimum benefits, standard provisions, or mandated benefits. Some state laws mandate that specific benefits be provided by insurance policies, while others mandate that the benefits at least be offered in the policies.128 At the end of 1984, there were 580 mandated

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128 Arkansas, Missouri and Texas are among the states that have adopted the "mandated optional benefits" approach.

benefits laws, some of which pertain directly to the field of medical rehabilitation (Demkovich, 1986). There are generally four types of mandated benefits laws. They require:

1) the coverage of health care services for specified populations (e.g., certain groups of disabled persons);

2) the coverage of specified health care services (e.g., certain rehabilitation services);

3) the coverage of health services provided by specified providers (e.g., services of physical therapists); and

4) the inclusion of specified conditions of insurance policy sale (e.g., option to continue employment-based group policy upon retirement or loss of job).

The insurance industry generally opposes mandated benefits laws, claiming that they reduce the insurer's flexibility to design an appropriate benefits package for a particular client, and that mandated benefits often cost more than they are worth.129 Insurers argue strongly that any decision on coverage must be based on considerations of the trade-offs between premium costs and the risks of the occurrence of a negative event, and that the purchaser of a policy should have the choice of whether or not to expend additional premium dollars to insure against specific risks. They also contend that insurance benefits are often determined by union and management negotiations in which wages and working conditions prevail over added insurance benefits (Rassmussen, 1987).

Proponents of the mandated benefits laws maintain that some mandated benefits are necessary to counter "market failures," particularly those associated with the underestimation by enrollees (or by companies developing plans for enrollees) of the likelihood of acquiring a particular illness or disability, or the underestimation of its cost. This market failure rationale appears particularly applicable to medical rehabilitation, because anecdotal evidence suggests that members of the general population substantially underestimate the likelihood of becoming disabled and are usually not familiar with the field of medical rehabilitation.

In addition to the market failure rationale, mandating benefits for rehabilitation and other health care services needed by the disabled population may be helpful in preventing the tendency of some insurers and HMOs actively to discourage disabled persons from enrolling in

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129 Some states, such as Arizona, Oregon, Pennsylvania, and Washington, now require a cost-benefit evaluation of any proposed mandated benefit. Arizona's law, for example, requires an analysis of social impact, including need, availability, hardship from lack of, and public demand for the proposed mandated benefit; and financial impact, including increases in costs and utilization that would result from mandating the benefit (Cornett, 1987).

their programs. Persons with disabilities tend to be high cost users of health care services, and are therefore considered "high-risk" populations by the insurance industry (Zook and Moore, 1980; Zook et al., 1980). They experience much higher rates of hospitalization than does the general population (Young et al., 1979; Meyers et al., 1985; Osberg et al., 1986). The tendency of insurance plans actively to attempt to discourage high-risk persons from enrolling in their plans is referred to as "preferred risk selection" (Enthoven, 1980).

An insurance plan could implement a strategy of preferred risk selection against disabled persons by failing to cover the basic services needed by many disabled persons (such as medical rehabilitation and durable medical equipment). Even those plans that do not wish to discourage enrollment of disabled persons may be deterred from covering a broad range of disability-related services. This is because they fear that disabled persons (or persons likely to become disabled) will be positively attracted to enrolling in their plans, thereby making their plans less competitive than those of competitors that practice preferred risk selection. The tendency of high-risk persons to seek plans that offer the extensive and intensive health care services they need is called "adverse selection."

Mandated coverage of disability-related services, such as medical rehabilitation, could counter the most extreme manifestations of both preferred risk selection and adverse selection. There are, however, a multitude of other subtle ways in which payors have discouraged disabled persons (and other persons with high medical risks) from enrolling in their programs, and mandated benefits would not necessarily remedy all preferred risk and adverse selection problems.130 Despite this important concern, mandated rehabilitation benefits would create a more "even playing field" for payors that wish to cover such services, but that would have been placed at a competitive disadvantage by doing so.

Thus, although there are valid arguments against legally mandating insurance benefits generally, there is also a strong theoretical basis for legally mandating coverage of medical rehabilitation services and other medical services for the disabled population. The American Speech-Language-Hearing Association (ASHA) has suggested a "coalition effort" of rehabilitation professionals to introduce legislation that would require mandated coverage for medical rehabilitation services

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130 These include the use of "pre-existing condition clauses" that limit coverage for treatment of certain illnesses and impairments, burdensome administrative requirements for payment of certain services, negative advertising practices and uncooperative plan employees that subtly discourage potential disabled enrollees, and physically inaccessible offices and treatment centers. Any plan to reform the health insurance or health care systems in this country must be sensitive to these subtle forms of discrimination and the tendency of some plans to attempt to "dump" disabled persons and other high risk enrollees to other plans.

(Cornett, 1987). The National Rehabilitation Caucus, whose participants include associations of providers and professionals, has lobbied extensively for coverage of inpatient and outpatient rehabilitation services in the proposed federal mandated benefits legislation.[131]

b. Federal Employees Health Benefits Program

The Federal Employees Health Benefits Program (FEHBP) is a congressionally enacted program in which a variety of traditional (e.g., Blue Cross/Blue Shield, Aetna, etc.) and prepaid (e.g., HMOs) health insurance plans compete for the enrollment of federal civilian employees.[132] During the annual "open season" (prior to the beginning of each enrollment year), federal employees are entitled to choose, based upon published plan benefits and premiums, one of the numerous available federally qualified plans. This system encourages health plans to compete rigorously with each other in meeting the needs of the enrolled population by providing a comprehensive set of covered services for a reasonable premium. The FEHBP has served as a model for many corporate health benefits programs in the private sector.

Plans under FEHBP generally offer a broader set of covered services than the average health care plan in the private sector. This is, in part, because Congress mandated a set of basic services that must be offered by FEHBP plans. Although medical rehabilitation is not explicitly included among the basic services under FEHBP, there are numerous FEHBP plans that cover rehabilitation. This includes many federally qualified HMOs that offer at least "short-term rehabilitation" (i.e., up to 60 days).[133] Since the "fee-for-service" plans under FEHBP must compete for enrollment with the prepaid plans, they also tend to cover at least "short-term rehabilitation."

c. Preferred Provider Arrangements (PPAs)

A preferred provider arrangement (PPA) is a negotiated agreement between a payor and a provider of health care services. Under the arrangement, the provider agrees to offer services at a discounted rate to enrolled members of the payor. In return, the payor directs its enrollees to the "preferred provider," typically by offering financial incentives for enrollees to use the provider. These incentives often include exempting enrollees who use preferred providers from paying otherwise applicable deductibles or copayments. The provider generally agrees to submit to utilization review for services provided. Services found to be unnecessary are not reimbursed (Johns et al., 1985; Kittrel, 1985; Lightfoot, 1985; Rice et al., 1985).

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[131] S. 1265, The Minimum Health Benefits Act of 1988 and H.R. 2508, the House companion bill, both introduced in the 100th Congress.

[132] Chapter 89 of Title 5, United States Code.

[133] "Short-term rehabilitation," one of the requirements for federal qualification of a prepaid plan, is discussed in section III.B(2) of this monograph.

Through preferred provider arrangements, payors are able to apply their financial leverage to induce providers to offer low rates, and to avoid medical interventions that are not cost-effective. Providers, in turn, are ensured a sufficient quantity of patients to maintain high quality services and to survive economically. Recently, some payors have been considering the establishment of preferred provider agreements with providers of medical rehabilitation. Except for some limited arrangements for the provision of some outpatient rehabilitation services, these PPAs have not been developed extensively at this time (England, 1986).

2) Health Maintenance Organizations (HMOs)

An HMO is a provider organization that offers a "comprehensive" set of covered health care services to its enrolled population in exchange for a predetermined fixed per capita payment per year (Luft, 1981; Luft, 1982). HMOs, therefore, have a strong incentive to contain the overall costs of their covered services per enrollee within their per capita payments (Manning et al., 1984). From 1971 to January 1985, the number of operational HMOs in this country increased from 33 to 377, and the number of HMO subscribers increased from 3.6 million to 16.7 million (HIAA, 1986). It is estimated that, at the end of 1987, there were 30 million HMO subscribers.

At present, some HMOs will cover up to 60 days of rehabilitation, if the HMO determines that the patient is likely to show a significant improvement in functioning during that time. This is consistent with the 60 day requirement established by the federal Health Maintenance Organization Act of 1973 for HMOs qualifying to receive federal assistance.134 Many non-federally-qualified HMOs, however, still do not cover rehabilitation. This may be due to the strong incentive for HMOs to contain costs and the consequent tendency to discourage high cost persons from enrolling in their programs.

a) HMOs and Medicare

Section 1876 of the Social Security Act sets forth the conditions under which an HMO or CMP may receive payment under Medicare. Such

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134 42 C.F.R. Section 110.102(a)(2)(ii) states that "inpatient hospital services and outpatient services shall include short term rehabilitation services and physical therapy, the provision of which the HMO determines can be expected to result in a significant improvement of a member's condition within a period of two months." It has been reported that some HMOs have interpreted a single physical therapy visit as a full day of rehabilitation for purposes of the 60 day requirement.

organizations may contract with HCFA on a risk basis (in which case they receive a single per capita payment per beneficiary equal to 95 percent of the actuarially expected costs of the beneficiary) or on a cost reimbursement basis. In either case, the plan must provide all services the beneficiary would otherwise be entitled to under Medicare, including all medical rehabilitation services.135

b) State law

Most states now have laws that regulate the activities of HMOs. These laws typically impose requirements on necessary financial reserves, open enrollments, prohibitions against discrimination against certain potential enrollees, and other provisions similar to those imposed on traditional health plans. Some states have imposed a basic set of benefits to be covered by HMOs in their states. According to NARF, no state has required its HMOs to offer rehabilitation. Connecticut has established a special task force on HMOs and rehabilitation to examine the issue.

c) Prepaid plans under the FEHBP

Federal regulations promulgated under the federal HMO Act require that federally qualifying prepaid plans must cover "short-term rehabilitation."136 Most prepaid plans offered to federal employees under the FEHBP (described in Section III B(1)(b)ii.b above) are federally qualified and conform to these regulations. The typical prepaid plan under the FEHBP contains the following limited benefits:

> "Short-term rehabilitative therapy (physical, speech and occupational therapy) is provided on an inpatient or outpatient basis for up to two months per condition if significant improvement can be expected within two months (you pay nothing per session). Speech therapy is limited to treatment of certain speech impairments of organic origin. Occupational therapy is limited to services which assist the member to achieve and maintain self-care and improved functioning in other activities of living."137

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135 See 50 Federal Register 1314 (Thursday, January 10, 1985).

136 42 C.F.R. Section 110.102(a)(2)(ii).

137 See 1988 FEHBP benefits pamphlet of the United Health Plan, a prepaid comprehensive medical plan serving Southern California. It is substantially similar to the provisions of all 20 other FEHBP prepaid plans in a sample reviewed by the author.

This provision is problematic for several reasons.138 First, since the obligation to provide rehabilitation is contingent upon a finding by the plan that can be achieved within two months, the provision is subject to arbitrary interpretations by the plans. This is particularly true because plans can save large amounts of money by failing to provide two months of rehabilitation, and many enrollees do not have the time, energy, or resources to contest an arbitrary decision through the FEHBP appeals process.139 Second, many severely disabled persons, including most persons with high level spinal cord injuries and brain injuries, require more than two months of medical rehabilitation to achieve optimal outcomes. Third, other limitations on types of therapies that will be covered exclude certain individuals that need such services and are also subject, in many cases, to arbitrary interpretations.

3) Disability Insurance Plans

Short-term and long-term private disability insurance plans protect workers and their families from the financial risk of disabilities that prevent them from pursuing their current jobs. Short-term plans typically cover persons with disabilities for a period up to 2 years; long-term plans usually cover persons disabled for at least 5 years. At the end of 1983, 87 million people, constituting 86 percent of employed civilians, had some form of disability coverage; 64 million people had short-term disability insurance; 25 million had long-term disability insurance; and 2 million had both (HIAA, 1986).

The primary enrollee benefit of disability insurance plans is the payment of lost wages due to disability. These plans generally set payment at a level not exceeding 60 percent of the salary earned at the occurrence of the disability.140 Some long-term private disability insurance plans will also pay on an ad hoc basis for medical rehabilitation not otherwise covered by health care insurance, provided that the plan of rehabilitation is acceptable to the insured individual, the physician, the rehabilitation facility, and the insurance carrier. A comprehensive plan of medical and vocational rehabilitation expediting return to work by the disabled individual could result in substantial savings for the long-term disability plan.

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138 The problems here are identical to the problems associated with the requirements for federally-qualified HMOs, which must adopt provisions that are essentially the same.

139 Plans may hesitate to implement arbitrary decisions denying rehabilitation if this is likely to give them a "bad reputation" and thus harm their competitive position. Few enrollees have the ability to publicize arbitrary decisions, so this concern is not likely to serve as a strong deterrent for a plan intent upon saving money by denying benefits.

140 Disability policies, however, may take many forms, and benefits may vary depending on the extent and nature of the enrollee's disability.

Eligibility for private disability benefits is based on the inability of an insured individual to perform the occupation for which the individual is qualified. This definition of disability is more "liberal" than that of the SSI and SSDI programs, which require that the individual be incapable of gainful activity. The period of time in which the disabled individual must be out of work to qualify for disability benefits varies among policies, ranging from one year to when the individual reaches age 65. The overall benefit period also varies from five years up to age 65. Many private plans also provide partial disability benefits for a limited period of time in cases where insured individuals are unable to assume their full pre-disability work capacities.

Most private long-term disability plans stipulate that claimants who are eligible for SSDI benefits must have the amount they receive from SSDI subtracted from the amount they receive from their private disability plan. Increasingly, private employers concerned with the rising cost of disability programs are closely monitoring their disabled employees' status to ensure that maximum offset is obtained from SSDI and from workers' compensation programs.

4) Self-Insured Organizations

In response to large increases in health insurance premiums by insurance companies, many large and medium-size organizations are choosing to provide directly their own in-house health insurance for their employees. Some are also self-insuring for their employees' disability insurance. In administering their plans, these organizations often use the administrative services of the insurance companies in Administrative Service Only Plans (ASO) and administrative and reinsurance services in Minimum Premium Plans (MPPs) (HIAA, 1986).[141]

In addition to avoiding health insurance premiums and thus enhancing their cash flows, self-insured employers are not subject to the inflexibility of state insurance regulations or the costs of state insurance premium taxes (Rublee, 1986). Under the Consolidated Omnibus Budget Reconciliation Act of 1985, group insurers are required to offer a conversion or continuation provision for individuals leaving the group (Woodyard and Foster, 1986). Also, several states mandate health benefits, including some rehabilitation services, for insurance policies. Self-insurers, however, do not fall under such laws, and therefore have a competitive advantage in planning their benefits packages.[142]

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[141] Approximately 39 percent of total 1983 insurance company group coverage (as compared to 5 percent in 1975) was for ASO and MPP corporate or other organizational self-funded health plans (HIAA, 1986).

[142] In Metropolitan Life Insurance Co. v. Massachusetts, 84-325 (Sup. Ct., decided June 3, 1985), the Supreme Court of the United States found that Massachusetts has an inherent police power to regulate insurance in the state and to require private insurers to

The Bureau of Labor Statistics' Report on Employee Benefits in Medium and Large Firms, the most comprehensive national study on health care and other benefits of employers, does not address coverage of medical rehabilitation services (BLS, 1987). Therefore, the full extent of rehabilitation coverage by self-insured employers (or, for that matter, by insurance plans of non-self-insured employers) is not known. It appears that rehabilitation coverage varies substantially among self-insured employers, depending on the employer's attitude toward disability management, understanding of medical rehabilitation, and the capacity of their disabled employees to return to the workplace.

C. Casualty Insurance

Any treatment of rehabilitation financing would be incomplete if it did not also consider insurance mechanisms for compensating persons injured in accidents caused by third parties. A casualty insurance policy is a contract between the insured and an insurance carrier in which the carrier agrees to reimburse the insured for (or to hold the insured legally harmless against) certain defined losses, in exchange for a premium paid by the insured. Such policies financially protect individuals and corporations, up to stated monetary limits, from legal liability resulting from a finding that the insured caused the injury of a third party (or from the costs of a monetary settlement of the case) (Magarick, 1988).

Traditionally, in the common law of negligence, known as "tort" law, legal liability for an injury had to be based on a finding of fault. A plaintiff had to prove that the defendant negligently and proximately caused an actual injury to the plaintiff. Under this system, a defendant employer was generally exculpated if the injury resulted from the normal risk of the injured employee's work (i.e., "assumption of risk"), if the negligence of a fellow worker of the injured employee was responsible for the injury (i.e., "the fellow-servant rule"), or if the injured worker was partially responsible for the injury (i.e., "contributory negligence") (Keeton and Keeton, 1977; Dobbs, 1985).

This fault-based liability system has been severely criticized by legal scholars for a number of reasons:

a) the injured party receives compensation only if fault and proximate causation of injury are established, leaving many uncompensated individuals destitute to become dependent on public assistance programs;

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offer certain benefits mandated by the state legislature. Self-insured corporations covered under the Employee Retirement Income Security Act (ERISA) are exempt from state insurance regulation, since Congress intended ERISA to preempt state laws which regulate employee welfare plans, including health benefits.

b) even if the injured individual prevails in court (i.e., all elements of a negligence claim having been established), the process typically takes so long that the individual must deplete all personal resources before the court orders compensation, often forcing a settlement;

c) compensation is unpredictable, and damage awards vary substantially for the same type of disability from case-to-case and from state-to-state;

d) a large percentage of the personal injury liability dollar (possibly as high as 53 percent) is spent on the cost of administering the system, such as salaries of insurance agents, insurance company profits, legal fees, and investigative costs, and relatively little goes to the injured persons; and

e) the system discourages early and effective rehabilitation, since the injured individual and his or her attorney often believe that interim rehabilitation may reduce the level of court damages awarded. (Keeton and Keeton, 1977; U.S. Chamber of Commerce, 1987).

Over the past eighty years, there has been a tendency for states to depart, however slowly, from the traditional system of fault-based legal liability coupled with casualty insurance. This trend is exemplified by the establishment of workers' compensation programs, "no fault" auto insurance laws, "strict" liability (i.e., liability without fault for certain types of injuries), and comparative negligence (i.e., reducing damage awards based upon the relative negligence of the injured party to that of the injuring party) (Dobbs, 1985).

The AHA Survey does not, at this time, disaggregate the rehabilitation revenues derived from the various forms of private sector "commercial insurance." It is, therefore, uncertain the extent to which casualty insurance pays for medical rehabilitation services. It appears that workers' compensation and automobile no-fault are the most important sources of rehabilitation payment among the various types of casualty insurance. Workers' compensation accounts for approximately one percent of gross inpatient revenues and five percent of gross outpatient revenues at rehabilitation facilities (Sonik, 1988). Although comparable statistics are not available for automobile no-fault, it is clear that no-fault insurance is growing rapidly, and accounts for an increasing share of the contribution by casualty insurers to the payment of medical rehabilitation.

Similarly, although there are no available statistics on percentage of rehabilitation revenues paid by automobile liability insurance and other traditional forms of casualty insurance, it appears that in the aggregate they pay for a smaller amount of medical rehabilitation services than does workers' compensation. Still, these types of insurance are an essential source of payment for some patients, and must not be ignored by the rehabilitation industry. Beyond their current significance, they are historically important because their shortcomings catalyzed the establishment of workers' compensation programs, auto no-fault insurance laws, and the public sector programs that are substantial payors of rehabilitation today (Keeton and Keeton, 1977; U.S. Chamber of Commerce, 1987).

1) Auto Liability/Auto No-Fault

Auto liability policies cover the owner of an insured vehicle, up to stated monetary limits, for harm caused by the vehicle to third parties, including pedestrians and persons in other vehicles. Such policies typically pay for "legal damages" awarded by a judge or jury according to traditional principles of fault-based liability, or for monetary settlements negotiated by the parties (i.e., the insurer and the injured person's attorney) in lieu of a court determination of liability. Damages or settlements generally include an amount reflecting the cost of medical care, including medical rehabilitation, if the injured party establishes the need for such care (Schermer, 1988).

If the injured individual is covered personally by his or her own casualty insurance policy, that policy is likely to pay for the individual's medical rehabilitation and other medical expenses, and then attempt to be reimbursed (often through legal action) from the casualty insurance policy of the party who caused the injury. To the extent that the injured individual does not have personal injury coverage, or that such coverage is limited in amount, the individual's only redress may be to bring a legal action against the party that caused the injury (Magarick, 1988). Due to the difficulty of prevailing in a negligence claim and the fact that many defendants have little if any liability coverage, it appears that relatively little medical rehabilitation is paid through the liability insurance of the injuring party.

In response to criticisms of fault-based liability systems, several states now have "no-fault" insurance laws for auto casualty, which mandate the payment for injuries and losses irrespective of negligence on the part of the insured. Under such systems, the medical and other costs of a person injured by an insured's car are paid by the insurance company that insured the car in amounts up to the state's statutory limit (if any). Once the state's limit has been reached, the injured individual generally can institute a lawsuit under state negligence law (Schermer, 1988).143 Therefore, even in no-fault states, the liability insurance of a negligent party who is legally liable for the injury may pay for at least some of the costs of medical rehabilitation services.

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143 In some states, injured persons relinquish their right to bring an action in court unless the injuries are "serious," meaning that they have reached a stated monetary threshold or meet a stated verbal description (i.e., serious impairment of a body function).

2) Personal and Commercial Liability Insurance

Personal liability insurance generally covers injuries caused by the insured on his or her property, such as certain accidents occurring at the home. Commercial general liability insurance covers harm caused by a business, such a professional malpractice and products liability. If legal liability is established (or a settlement is reached) for a disabling injury caused by, for example, a negligently maintained stairway, a negligently performed survey, or a dangerously defective product, it may be covered by a personal or general commercial liability insurance policy. Like auto liability insurance, these types of insurance pay on behalf of the insured individual or company for damages awarded pursuant to state negligence law. They pay an amount reflecting the cost of medical rehabilitation if the need for such services is established and included in the award or settlement (Magarick, 1988).

3) Workers' Compensation

Workers' compensation was the first form of legislatively mandated "social insurance" to develop widely in the United Sates. The first workers' compensation was established by the federal government for its civilian employees in 1908. There are now 53 separate non-federal workers' compensation programs, one in each state, plus the District of Columbia, Puerto Rico, and the Virgin Islands (U.S. Chamber of Commerce, 1987). There are also federal workers' compensation programs for civilian employees, longshoremen, and harbor workers, and a program compensating coal miners with "black lung" disease (SSA, 1986).

The basic concept underlying the workers' compensation laws is to provide a mechanism for alternative dispute resolution at the workplace, thereby relieving employers of liability for negligence, and relieving employees of the need to initiate law suits in order to receive any compensation for injuries (Malone et al., 1980). Each state (or territory) has a separate independent workers' compensation program, and there is considerable variation among programs based upon the laws of the various jurisdictions. The common element among workers' compensation laws is that employers assume the costs of occupational disabilities without regard to fault (U.S. Chamber of Commerce, 1987).

Methods of financing workers' compensation programs vary somewhat among states, although in all cases employers bear nearly all of the costs of insuring against liability for work-related illness or injury. Most states require employers to obtain commercial insurance or to offer proof of financial ability to self-insure. A number of states also operate special state insurance funds (U.S. Chamber of Commerce, 1987). Workers' compensation programs are major sources of coverage for medical rehabilitation services for non-elderly adults with occupational disabilities. Workers' compensation also represents an important source of referrals from insurance and self-insured entities to rehabilitation providers (Kreider and Wissel, 1985).

a) Eligibility for Workers' Compensation

Most employees are eligible to receive benefits under workers' compensation programs in the event they are injured or disabled at the workplace. In all states except New Jersey, South Carolina, and Texas, employers are required to acquire workers' compensation coverage for their employees. Various states exclude different categories of workers from their programs (U.S. Chamber of Commerce, 1987). Actual eligibility for workers' compensation benefits is based on the determination that a given injury or disability has arisen "out of or in the course of employment" (Larson, 1985; Malone et al., 1980).

The definition of disability employed by workers' compensation programs is generally much less restrictive than that employed in the federal SSDI/SSI programs. Individuals claiming workers' compensation benefits must show only that they are unable to perform their former employment or to obtain employment suitable to their qualifications and training (Malone et al., 1980; Larson, 1985). Although workers' compensation benefits were originally intended largely for victims of industrial accidents, in recent years workers' compensation laws have been broadened to make benefits available to individuals who have occupational diseases as well (Larson, 1985; SSA, 1986).

Because determining the causes of ailments such as heart disease or respiratory problems is difficult, and the precise contribution of the workplace environment toward such diseases is often impossible to ascertain, workers' compensation laws in many states contain features that limit employer liability. These include provisions excluding diseases that are "ordinary diseases of life" and that are not "peculiar to or characteristic of" the employee's occupation. In addition, many states restrict coverage of diseases with long latency periods by imposing time limitations on both the onset of disability and the filing of workers' compensation claims. Often, a disability claim must be filed within one to three years from the time of last exposure to the cause of the disability (Larson, 1985; SSA, 1986).

Although all workers' compensation programs provide coverage for medical services and medical rehabilitation services, the use of such services can be hindered in cases where the employer and employee are contesting a benefit claim. In such cases, the employee may perceive a strong incentive to maintain his or her "disabled" status by not actively participating in rehabilitation activities. Similarly, in certain circumstances, the relatively high weekly wage replacement benefits for which some workers are eligible may also act as a disincentive to their acceptance of the rehabilitation services that might assist them to return to work.

b) Workers' Compensation Benefits/Payment Policies

In recent years, the cost of workers' compensation programs has risen dramatically for employers, soaring from a total cost of $5 billion in

1970 to $30 billion in 1985 (SSA, 1986; Chamber of Commerce, 1987). A large part of this increase is due to the major changes in benefit structures implemented in many states during the 1970s. Another very significant factor has been the increasing cost of medical benefits provided under workers' compensation programs.

Hospital and medical expenditures by workers' compensation program rose from $0.8 billion in 1964 to $6.4 billion in 1983 (HIAA, 1986).144 This is due, in part, to inflationary cost- or charge-based payment systems used by many of the programs. Like other payors of medical rehabilitation, workers' compensation programs will be reassessing their payment policies for medical and other benefits in the coming decade. There are several models available for the payment of medical rehabilitation services, but it is uncertain at this time which, if any, of these payment models will be adopted by the programs (Batavia, 1988).

Three types of benefits are available under workers' compensation programs:

- Cash benefits--available either periodically or as a lump sum to compensate the employee for loss of income or earning capacity due to temporary or permanent disability. In cases of significant permanent disability, both a lump sum payment and periodic benefits may be made. The amount of periodic cash benefit payments averages two-thirds of wage loss, subject to maximum benefit limits. Lump sum settlements are often made according to a schedule of permanent impairments established by a state. Such settlements generally do not affect the amount received as a periodic benefit (Larson, 1987).

- Medical benefits--provided immediately upon a finding of eligibility for benefits, usually with no limitations on total cost of treatment or length of time in treatment. Medical benefits include emergency care, necessary medical rehabilitation, and other required care for the disabled worker. Payment is typically provided on a charge basis, with no deductibles or copayments borne by the worker (Larson, 1987).

- Rehabilitation benefits--all of the workers' compensation programs provide for vocational and medical rehabilitation, as it is needed by the beneficiary. Fourteen jurisdictions directly

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144 This increase has contributed to the growing interest in "disability management" on the part of large employers who have the technical capacity to analyze the total costs of their disability programs. Rehabilitation services are viewed as an integral part of disability management programs. The growth of such programs has thus resulted in considerable growth in the private rehabilitation industry, particularly in the vocational rehabilitation sector.

operate rehabilitation facilities under the workers' compensation program, while the others provide for the reimbursement of outside rehabilitation providers (SSA, 1986). Also, vocational rehabilitation, retraining programs, and special maintenance benefits are provided under most programs to assist the beneficiary in resuming gainful employment after medical rehabilitation has been completed (Chamber of Commerce, 1987).

D. Analysis of Private Sector Payors

The private sector finances medical rehabilitation services through two general types of insurance: (1) health and disability insurance that covers the insured person (such as traditional health insurance, prepaid health plans, and long-term disability insurance), and (2) casualty insurance that financially protects the insured from harm caused to other persons (such as liability insurance, no-fault insurance, and workers' compensation). As discussed above, each category of insurers or other entities that implement these insurance mechanisms has a different set of obligations or incentives to cover medical rehabilitation services.

Disability insurers generally have an obligation to make payments to the disabled beneficiary for an extended period of time, as defined by their policies, in order to provide compensation for lost income. Some insurers attempt to determine whether they can reduce their financial liability for a beneficiary by providing medical and vocational rehabilitation to the individual. If it is determined by the disability insurers that medical and/or vocational rehabilitation will result in a disabled person's recovery of optimal function and return to work, the insurer may have a strong incentive to cover such services.

Similarly, carriers of workers' compensation or casualty insurance, to the extent that they have a long-term obligation to make payments to the injured, may have a strong incentive to encourage rehabilitation. Casualty insurers subject to a valid claim are generally required to make a lump sum payment or a series of payments over time, which often includes the expected cost of medical rehabilitation services. To the extent a casualty insurer can demonstrate that the injured party can regain his or her earning power through rehabilitation, this could reduce the insurer's long-term financial liability. This is also true of workers' compensation, though carriers of workers' compensation typically are also specifically obligated by law to cover medical rehabilitation.

Health insurers, on the other hand, often only have an obligation to pay for rehabilitation if the applicable state law mandates such coverage or if they voluntarily choose to cover rehabilitation explicitly in their policies. They may have little incentive to cover rehabilitation services, since, unlike disability insurers, they have no ongoing financial obligation to the disabled enrollee (and since coverage of rehabilitation would increase premiums).145 This is similarly true of HMOs, which have even stronger incentives to contain costs, and thus not to cover high cost rehabilitation services. It must be recognized, however, that the payor's less costly option in the short run--to restrict rehabilitation coverage--is not necessarily the most cost-effective solution from the perspective of the patient or society or possibly even the payor in the long run (Batavia, 1988).

More research is needed on the strengths of the incentives for private sector payors to finance medical rehabilitation services, and on the behavior actually induced. Concerns over becoming less competitive due to adverse selection suggest that health insurers and HMOs often have little incentive (and may have a strong disincentive) to cover medical rehabilitation services on a explicit contractual basis. Preferred risk selection by health insurers and HMOs may, therefore, be a substantial deterrent to the coverage of medical rehabilitation. It is essential that the rehabilitation and disability communities understand adverse selection and preferred risk selection to determine if these phenomena are, in fact, significantly reducing access to medical rehabilitation and other service needed by disabled persons.

Further evidence of the cost-effectiveness of medical rehabilitation also is needed to convince payors that they should include rehabilitation as an explicitly covered service in their policies. Such research, in conjunction with public education on the benefits of rehabilitation, may result in enhanced pressures by enrollees on health insurers and HMOs to cover medical rehabilitation services. Due to adverse selection and preferred risk selection, however, additional measures may prove to be necessary. These measures could include mandating coverage of rehabilitation benefits and making health insurers and HMOs financially liable for the negative consequences of failing to cover rehabilitation. It is uncertain at this time how such measures would be ideally devised and implemented.

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[145] Insurers would have such an incentive if coverage of rehabilitation services in their insurance contracts is strongly requested by potential enrollees (or their representatives). It appears that most enrollees do not contemplate the need for rehabilitation services until they actually need them.

IV. CONCLUSIONS

This monograph describes the major payors of medical rehabilitation services. It discusses the eligibility, coverage, and payment policies of a wide variety of programs implemented by a broad scope of public and private sector payors of rehabilitation. These programs and policies differ substantially from each other, from payor-to-payor, state-to-state, and program-to-program. Therefore, few generalizations can be made about the financing of medical rehabilitation services in this country. Each program must be considered and analyzed separately to determine its effect on the access, quality, costs, and outcomes of rehabilitation for persons covered by them.

Despite this, there are some important features of the larger public sector programs, and some common elements among the various categories of private sector programs, that should be emphasized. For example, eligibility rules vary substantially based upon the primary purpose of each program. Eligibility depends largely on age or amount of time disabled for Medicare; income and resources for Medicaid; service-connected disability or financial resources for the Veterans Administration programs; extent of disability and employment potential for vocational rehabilitation programs; employment and financial resources for private health insurance and disability insurance; and injury by an insured individual or organization for casualty insurance and workers' compensation.

Coverage rules for rehabilitation similarly vary substantially from program-to-program. They tend to be very carefully defined through regulations and other publications for the public sector programs and workers' compensation; less formally defined for most private sector health insurance programs; and largely ad hoc for disability and casualty insurance programs. Payment rules continue to be based primarily on cost or charge-based retrospective reimbursement for the vast majority of rehabilitation payors, including Medicare, Medicaid, private health insurance, and workers' compensation. Prospective payment systems and preferred provider arrangements are being considered and developed by some payors, and capitation payment is used by the growing number of federally-qualified (and other) HMOs and prepaid plans that cover rehabilitation.

This monograph provides the most comprehensive description to date of the payors that finance medical rehabilitative care. It does not, however, attempt to analyze extensively whether these programs and their policies are adequate to meet the short-term and continuing care needs of persons with disabilities.146 In fact, these programs do not fully meet all these needs (NARF, 1983). Medicare does not cover ex-

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146 Further, this monograph does not examine in depth how the various public sector programs are actually being implemented in practice. For example, HCFA implements its statutory responsibilities in administering the Medicare and Medicaid programs through the publica-

tended or custodial care, including the ongoing rehabilitation services needed by many disabled persons in the long-term. Medicaid, depending on the state, may provide a broader range of services, but has very restrictive eligibility requirements resulting in non-coverage of many working poor persons who require rehabilitation. Private sector coverage of rehabilitation depends largely upon the obligations imposed on payors by law or voluntarily incorporated into their policies, and the incentives associated with those obligations.

With the exception of "coordination of benefits" provisions used by some payors in their policies to reduce their own financial liability, there has been little attempt by payors to coordinate the provision or payment of medical rehabilitation services. The "system" of financing for medical rehabilitation services in this country, like the health care financing "system" generally, is largely fragmented. This has resulted in over-coverage for some persons, under-coverage for other persons, and no coverage whatsoever for a growing number of Americans in need of medical rehabilitation services.

This monograph also has not focused on how the financing of medical rehabilitation is likely to evolve over time. Due to perceived inefficiencies and inequities resulting from the fragmentation of the health care financing system, the author believes that a comprehensive National Health Insurance Program for the entire population eventually will be adopted in this country. This does not appear likely for at least a decade, and it is uncertain at this time how such a system would be designed and organized.147 Hopefully, if and when developed, such a system would provide broad coverage of medical rehabilitation and other long-term services needed by disabled persons. In the interim, it would be valuable to develop a national approach (i.e., a federal plan) to coordinate the policies of the multitude of public

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tion of federal regulations and manual provisions, and through the interpretations of the insurance carriers that serve as Medicare financial intermediaries. It is possible that some interpretations by HCFA or its intermediaries add to, or illegally conflict with, statutory or regulatory standards.

147 Inevitably, any National Health Insurance Program that may develop will not be based on a model of socialized medicine or nationalization of health insurance, nor should it be. The author predicts that the national health insurance system that would be adopted would be highly decentralized but coordinated through the federal government, and would utilize much of the current health insurance and health care industry for implementation. Such a program has been designed by Professor Alain Enthoven at Stanford, and would include coverage of a comprehensive set of health care services, including medical rehabilitation (Enthoven, 1980). Until such a program is developed and implemented, we can expect a continuation of incremental increases in coverage for rehabilitation services by the current payors of medical rehabilitation.

and private sector payors and programs that currently finance medical rehabilitation and health care generally.

This NARF monograph, therefore, provides only a first step in fully understanding current and potential mechanisms for financing medical rehabilitation services. More research is needed to determine how these programs are being implemented in practice; how they affect rehabilitation providers and the provision of rehabilitation services; how they affect disabled persons (the ultimate consumers of medical rehabilitation services); and how they should be appropriately applied and modified. In this era of fiscal austerity and in an increasingly competitive medical rehabilitation environment, such knowledge will provide valuable insight on which models and mechanisms of health care financing should be adopted by the payors of rehabilitation.

BIBLIOGRAPHY

Batavia, A.I., The Payment of Medical Rehabilitation Services: Current Mechanisms and Potential Models, American Hospital Association, Chicago, 1988.

Batavia, A.I. and DeJong, G., "Prospective Payment for Medical Rehabilitation: The DHHS Report to Congress," Archives of Physical Medicine and Rehabilitation, 69(5): 377-80, May 1988.

Bureau of Labor Statistics (BLS), Employee Benefits in Medium and Large Firms, Washington, D.C., June 1987.

Carbine, M.E. and Schwartz, G.E., Strategies for Managing Disability Costs, Washington Business Group on Health/Institute for Rehabilitation and Disability Management, Washington, D.C., 1987.

Costich, J.F., "Change in Rehabilitation Outcomes under PPS and PRO," (Paper presented at the annual meetings of the National Association of Rehabilitation Research and Training Centers, Washington, D.C., May 1985), University of Kentucky Department of Rehabilitation Medicine, 1985.

Costich, J.F., "Acute Care Prospective Payment: Impact on Medical Rehabilitation Outcomes" in Rehabilitation Outcomes: Analysis and Measurement (M. Fuhrer, ed.), Paul H. Brookes, Baltimore, London, 1987.

Cornett, B.S., "Mandated Benefits - Pros and Cons," ASHA State Policy Workshop, Washington, D.C., May 7, 1987.

Cowell, M.J. and Hoskins, W.H., AIDS, HIV Mortality, and Life Insurance, The Society of Actuaries, Chicago, August, 1987.

DeLisa, J., "Diagnostic Related Groups (DRGs) and Rehab Medicine in the Veterans Administration," Archives of Physical Medicine and Rehabilitation, 66: 125, February, 1985.

Demkovich, L.E., "Covering Options Through Mandated Benefits" Business and Health, 3(3): 27-29, Jan-Feb 1986.

Department of Health and Human Services (DHHS), Report to Congress: Developing a Prospective Payment System for Excluded Hospitals, October, 1987.

Department of Health and Human Services (DHHS), Report to Congress: Prospective Payment for Hospitals, December 1982.

Dobbs, D.B., Torts and Compensation: Personal Accountability and Social Responsibility for Injury, West Publishing Co., St. Paul, Minnesota, 1985.

Eazell, D.E. and Johnson, M.V., The Cost Benefits of Stroke Rehabilitation, National Association of Rehabilitation Facilities, Washington, D.C., 1981.

Eckenhoff, E.A., "Medical Rehabilitation in the 1980s," Health Care Management Review, 6(2): 55-62, 1980.

Eckenhoff, E.A., "Rehabilitation: Ghosts . . . Images . . . Visions," Archives of Physical Medicine and Rehabilitation, 67: 75-78, 1986.

England, B. (editor), Medical Rehabilitation Services in Health Care Institutions, American Hospital Association, Chicago, 1986.

England, B., Amkraut, C., and Lesparre, M., An Agenda for Medical Rehabilitation: 1987 and Into the 21st Century, A paper prepared for the Institute for Rehabilitation and Disability Management (IRDM) and American Hospital Association Section for Rehabilitation Hospitals and Programs (AHA), 1987.

Enthoven, A.C., Health Plan: The Only Practical Solution to the Soaring Cost of Medical Care, Addison-Wesley Publishing Co., Reading, MA, 1980.

Fetter, R.B., Freeman, J.L., and Mullin, R.L., "DRGs: How They Evolved and are Changing the Way Hospitals are Managed," Pathologist, XXXIX(6), June, 1985.

Gorski, R., "1619: It's a Working Number," Disabled U.S.A., 1985(1), 13-15, 1985.

Health Care Financing Administration Office of Intergovernmental Affairs (HCFA), "Medicaid Services State by State: Optional Services in State Medicaid Programs," HCFA Pub. No. 02155-88, 1988.

Health Insurance Association of America (HIAA), "Speciality Hospitals and Insurance Coverage," Washington, D.C., July 26, 1978.

Health Insurance Association of America (HIAA), Source Book of Health Insurance Data, 1984-85, HIAA Public Relations Division, Washington, D.C., 1986.

Health Insurance Association of America (HIAA), "Survey of Rehabilitation Programs Offered by Member Companies," Research and Statistical Bulletin, No. 2-87, March 20, 1987.

Health Insurance Association of America (HIAA), "Insurance, Managed Care and Provider Relations Bulletin," Number 10-88, April 18, 1988.

Hosek, S.; Kane, R.; Carney, M.; Hartman, J.; Reboussin, D.; Serrato, C.; and Melvin, J., "Charges and Outcomes for Rehabilitative Care: Implications for the Prospective Payment System," Rand Corporation, Santa Monica, California, 1986.

Intergovernmental Health Policy Project (IHPP), "The Risk Pool Strategy: Comprehensive Health Insurance Associations," Focus On ..., No. 20, February 1988.

Johns, L, Anderson, M.D., and Derzon, R.A., "Selective Contracting in California: Experience in the Second Year," Inquiry, 22: 335, 1985.

Johnson, M.V. and Keith, R.A., "Cost-Benefits of Medical Rehabilitation: Review and Critique," Archives of Physical Medicine and Rehabilitation, 64(4): 146-54, 1983.

Keeton, P. and Keeton, R.E., Torts: Cases and Materials, 2nd Ed., West Publishing Co., St. Paul, Minnesota, 1977.

Kittrel, A., "PPOs Cut Employer Health Care Costs: Survey," Business Insurance, 19(46): 20-21, 1985.

Knable, J.C., "Case Management Today and Tomorrow: The Insurance Setting," Coordinator, 5(3): 20-21, 1986.

Kreider, J.R. and Wissel, E., The Privates: Principles of Insurance Rehabilitation, National Association of Rehabilitation Facilities, Washington, D.C., January 1985.

Kottke, F.J., Stillwell, G.K. and Lehmann, J.F., Krusen's Handbook of Physical Medicine and Rehabilitation (Third Edition), W.B. Saunders Company, 1982.

Lightfoot, D.G., "Preferred Provider Organization Concepts and Arrangements," Risk Management, 32(11): 28-36, 1985.

Larson, A., The Law of Workmen's Compensation, Matthew Bender, New York, 1985 (Volume I) and 1987 (Volume II).

Luft, H.S., Health Maintenance Organizations, New York: John Wiley & Sons, 1981.

Luft, H.S., "Health Maintenance Organizations and the Rationing of Medical Care," Milbank Memorial Quarterly Fund, 60(2): 268-306, 1982.

Magarick, P., Casualty Insurance Claims: Coverage/Investigation/Law, Clark Boardman Co., New York, 1988.

Malone, W.S., Plant, M.L., and Little, J.W., Cases and Materials on Workers' Compensation and Employment Rights, second edition, West Publishing Co., St. Paul, Minnesota, 1980.

Manning, W.W.; Leibowitz, A.; Goldberg, G.A.; Rogers, W.H.; and Newhouse, J.P., "A Controlled Trial of the Effect of a Prepaid Group Practice on Use of Services," New England Journal of Medicine, 310(23): 1505-1510, June 7, 1984.

McGinnis, G.E.; Osberg, J.S.; DeJong, G.; Mae, M.; Seward, L.; and Branch, L.E., "Predicting Charges for Inpatient Medical Rehabilitation Using Severity, DRG, Age, and Function," American Journal of Public Health, 77(7): 826-829, 1987.

Meyers, A.R.; Felton, M.; Master, R.J.; Nicastro, D.; Cupples, A.; Lederman, R.I.; and Branch, L.G., "Rehospitalization and Spinal Cord Injury: Cross Sectional Survey of Adults Living Independently," Archives of Physical Medicine and Rehabilitation, 66: 704-708, 1985.

Mittelmann, M., "Rehabilitation Issues From an Insurer's Viewpoint: Past, Present and Future," Archives of Physical Medicine and Rehabilitation, 61(12); 587-91, 1980.

Mittelmann, M., "Insurance and Rehabilitation," in Current Therapy in Psychiatry-Physical Medicine and Rehabilitation, W.B. Saunders Company, Philadelphia, 1984.

Mittelmann, M. and Settele, J., "Insurance Reimbursement Mechanisms for Rehabilitation Equipment and Environmental Modification," Archives of Physical Medicine and Rehabilitation, 63: 279-83, June 1982.

National Association of Rehabilitation Facilities (NARF), Report to Rehabilitation Facilities on Tax Equity and Fiscal Responsibility Act of 1982, Washington, D.C., 1982.

National Association of Rehabilitation Facilities (NARF), Catastrophic Health Insurance and the Rehabilitation Patient, Washington, D.C., 1983.

National Association of Rehabilitation Facilities (NARF), Exclusion of Rehabilitation Hospitals and Rehabilitation Units from the Medicare Prospective Payment System: How it Works, Washington, D.C., 1984.

National Association of Rehabilitation Facilities (NARF), NARF Position Paper on a Prospective Payment System for Inpatient Medical Rehabilitation Services and a Study Regarding a Prospective Payment System for Inpatient Medical Rehabilitation Services: Final Report, (Study conducted by Coopers and Lybrand), Washington, D.C., 1986.

National Association of Rehabilitation Facilities (NARF), Comprehensive Outpatient Rehabilitation Facilities: The New Medicare Providers: Analysis and Guide: Updated June 1986, Washington, D.C., 1986.

National Association of Rehabilitation Facilities (NARF), Statement of the National Association of Rehabilitation Facilities Regarding Payment for Inpatient Medical Rehabilitation Services Under the Medicare Program, Washington, D.C., January 1988.

National Head Injury Foundation (NHIF), Traumatic Head Injury: A Review of Gaps and Problems in Insurance Coverages, A report of the National Head Injury Foundation Insurance Committee, February, 1988.

Ohio Self-Insurers Seminar, The Self-Insured Employer and Rehabilitation: A Disability Management Model, Mitchell, K., Rehabilitation Division, Industrial Commission of Ohio, April 1982.

Osberg, J.S.; McGinnis, G.E.; Seward, M.L.; DeJong, G.; Branch, L.G.; White, H.C.; Pomfret, A.; and Campion, E.W., "Rehospitalization Following Rehabilitation: Findings and Analysis," Paper presented at the annual meeting of the American Congress of Rehabilitation Medicine, Baltimore, MD, October 10, 1986.

Rassmussen, B., "Mandated Coverage: An Employer Debate," Business and Health, 12-14, April 1987.

Reeb, K.G., Jr., Private Insurance Reimbursement for Rehabilitation Equipment, Electronic Industries Foundation Rehabilitation Engineering Center, Washington, D.C., July 1987a.

Reeb, K.G., Jr., Final Report of the National Task Force on Third Party Payment for Rehabilitation Equipment, Paralyzed Veterans of America and Electronic Industries Foundation, Washington, D.C., September 1987b.

Reeb, K.G., Jr., Procurement of Durable Medical Equipment Under the Medicare Part B Program, Electronic Industries Foundation Rehabilitation Engineering Center, Washington, D.C., 1987c.

Reeb, K.G., Jr., Revolving Loan Funds: Expanding Equipment Credit Financing Opportunities for Persons with Disabilities, Electronic Industries Foundation Rehabilitation Engineering Center, Washington, D.C., June 1987d.

Rehabilitation Services Administration (RSA), State Vocational Rehabilitation Agency Program Data: Fiscal Year 1985, Department of Education, Washington, D.C., 1986.

Rice, T.; de Lissovoy, G.; Gabel, J.; and Ermann, D., "State of PPOs: Results from a National Survey," Health Affairs, Winter 1985: 25-40, 1985.

Rublee, D.A., "Self-Funded Health Benefit Plans: Trends, Legal Environment, and Policy Issues," Journal of the American Medical Association, 255(6): 787-89, 1986.

Rusk, H.A., "Rehabilitation Medicine: Knowledge In Search of Understanding," Archives of Physical Medicine and Rehabilitation, 59: 156-160, 1978.

Scadden, L., Stimulating the Manufacturing and Distribution of Rehabilitation Products: Economic and Policy Incentives and Disincentives, Electronic Industries Foundation, Washington, D.C., September, 1987.

Schermer, I.E., *Automobile Liability Insurance*, Clark Boardman Co., New York, 1988.

Social Security Administration (SSA), "Social Security Programs in the United States," *Social Security Bulletin*, 49(1): 5-59, January 1986.

Sonik, S., *Medical Rehabilitation Hospitals and Units: A Summary and Comparison Between 1984 and 1986 Surveys*, Conducted by the American Hospital Association Section for Rehabilitation Hospitals and Programs and the Hospital Data Center, American Hospital Association, Chicago, June 1988.

Sulvetta, M. and Schwartz, K., *The Uninsured and Uncompensated Care: A Chartbook*, National Health Policy Forum, Washington, D.C., 1986.

Thompson, F.A., Melnyk, Z.L., and Rao, N.V., *Underwriting and Actuarial Considerations Associated with Providing Health Care coverage to Special Risk Groups*, Paper presented by Dr. Thompson at the "Working Group Meeting on Public and Private Health Insurance Practices Effecting Disabled Individuals," sponsored by NIDRR, Washington, D.C., June 14-15, 1988.

Urban Institute, *The Changing Face of the Uninsured*, New York, June 1984.

U.S. Chamber of Commerce, *1987 Analysis of Workers' Compensation Laws*, Washington, D.C., 1987.

U.S. Department of Commerce, Bureau of the Census, Current Population Reports, Household Economic Studies, *Economic Characteristics of Households in the United States: Fourth Quarter, 1983*, Washington, D.C., 1983.

Veterans Administration (VA), *Clinical Affairs: Prosthetic and Sensory Aids Service*, (issued by the VA Department of Medicine and Surgery), May 29, 1986.

Veterans Administration (VA), *Annual Report 1986*, Administrator of Veterans Affairs, Washington, D.C., June 1987.

Woodyard III, W.H.L. and Foster. S.D., "The Regulatory Obstacles Posed by Self-Insurance," *Business and Health*, 3(3): 24, 1986.

Young, J.S. and Northup, N.E., "Rehospitalization in Years Two and Three Following Spinal Cord Injury," *Spinal Cord Injury Digest*, 1: 21-26, 1979.

Zollar, C., "Impact of Prospective Payment DRGs on Rehabilitation Services," *Coordinator*, 4(3): 28-29, 1985.

Zook, C.J. and Moore, F.D., "High-Cost Users of Medical Care," The New England Journal of Medicine, 302: 996-1002, 1980.

Zook, C.J., Savickis, S.F., and Moore, F.D., "Repeated Hospitalization for the Same Disease: A Multiplier of National Health Costs," Milbank Memorial Fund Quarterly, 58(3): 454-71, 1980.

AFT AMERICAN FEDERATION OF TEACHERS AFL-CIO
555 NEW JERSEY AVENUE, NW
WASHINGTON, DC 20001
202/879-4400

ALBERT SHANKER
President

November 21, 1989

Honorable John D. Rockefeller IV
Chairman, The Pepper Commission
140 Cannon House Office Building
Washington, D.C. 20515

Dear Mr. Chairman:

The members of the American Federation of Teachers and its health care division, the Federation of Nurses and Health Professionals, are greatly concerned with the health and well-being of our nation and the present state of its health care industry. Our sense of concern stems from various perspectives: We are concerned as consumers struggling to afford health care for ourselves and our families. We are concerned as health care providers who find it increasingly difficult to face the challenge of providing high-quality health care and know there are so many who are unable to secure such.

For these reasons, and many more, we applaud the Commission for its laudable efforts and goals as it works to find comprehensive solutions to the problems of access to health care and long-term care. And, in the enclosed testimony, we offer what we hope will be useful strategies in achieving those goals.

We eagerly anticipate the recommendations of the Pepper Commission and look forward to supporting them.

Sincerely,

Albert Shanker

LONG-TERM CARE: A National Need

American Federation of Teachers, AFL-CIO
November 21, 1989

OVERVIEW: In 1989, an estimated 7.1 million Americans will require long-term care, that is, assistance with one or more of the activities of daily life such as eating, dressing, bathing, toileting or transferring. About 23 percent of this group will receive such care in nursing homes, where the average cost of care per year now exceeds $25,000. Nearly half the elderly living alone will exhaust their income and assets after just 13 weeks of nursing home care. There are also today about 4 million working-age non-elderly adults and children with a major activity limitation or disability that requires some long-term care. Although the U.S. is now spending about $46 billion a year on long-term care, we still have virtually no organized system to deliver custodial care to seniors in their own homes. Eighty-five percent of all home care is delivered by family members and friends, one third of whom live in poverty.

FINANCING: Private insurance for long-term care covers only 1.4 percent of seniors. Policies vary greatly in the extent of coverage and value. For example, most cover only a fixed time period (typically two to four years) and do not cover Alzheimer's disease. State regulation of the long-term insurance market is spotty. There is no current federal regulation. Medicare covers only about 2 percent of nursing home expenses. Medicaid funds 41 percent of nursing home care but only 12 percent of home care. It also requires virtual impoverishment as a prelude to eligibility. Today patients and their families pay 51 percent of nursing home costs, up from 44 percent in 1980. The cost of long-term care is the primary health-related cause of financial ruin among the elderly.

DEMOGRAPHICS: The estimated number of disabled elderly Americans is expected to nearly double between 1989 and 2020 (7.1 million to 12.3 million). The corresponding numbers for those living in the community are 5.5 million and 6.7 million. Today, an estimated 40 percent of these men and women are not receiving the care they need. With increased longevity and decreased availability of family-based care, the demand for long-term care both in and out of nursing homes will reach crisis proportions while the supply of family caregivers will shrink drastically.

RECOMMENDATIONS:

*Long-term care is a family issue. Any comprehensive program must be available to all generations: to chronically ill children and severely disabled working-age adults as well as disabled people over 65.

*Long-term care should be delivered through a mix of public and private programs with strict safeguards to insure quality, determine eligibility and control costs.

*Quality assurance mechanisms should include mandatory training for and regular review of all caregivers, a home care consumer bill of rights, community review and effective enforcement mechanisms to ensure quality. Such mechanisms should also encourage decent wages and benefits for paid caregivers.

* State government -- through its licensing and regulatory agencies -- should take an active role in quality assurance by imposing financial penalties and / or removing licenses of individuals or institutions that violate quality standards.

*Such care should be delivered in the setting that fosters the greatest degree of personal independence: in the home rather than the nursing home; in an elder care center rather than a hospital. The AFT favors a continuum of care approach that would include: medical, nursing and social home care; respite care, including vacations and guaranteed unpaid leave from employment for family members who provide home care; rehabilitation and speech therapy; community care centers, including transportation; and nursing home care as a last resort. Such a program should also include financial incentives to encourage families who can do so to provide the care themselves.

*Long-term care benefits and eligibility should be administered under a cooperative arrangement utilizing an individual's physician and an independent professional case management team. Eligibility should be determined by failure to perform one or more activities of daily living and cases should be reviewed regularly to assess continued eligibility as well as requirements for care.

*Since it would benefit all age groups, a comprehensive long-term care program should be financed by all generations. As the recent unhappy experience with federal Medicare catastrophic insurance has demonstrated, benefits targeted to and financed by one age group divide Americans. A long-term care program could be financed in a number of ways, including eliminating the cap on the Medicare and Social Security payroll tax or eliminating the bubble in the federal income tax code. The AFT could support a system of modest co-payments for individuals above the poverty line but would oppose a means-tested system.

*Finally, we believe that the most effective long-term care program would be part of a comprehensive national health care system that includes stepped-up efforts to contain medical costs, increased emphasis on preventive care and intensified research to reduce the toll and cost of chronic illness.

HEALTH CARE ACCESS FOR ALL AMERICANS: A National Right

The Pepper Commission has offered three options to assist in the development of a plan to provide accessible health care for all Americans. The Federation of Nurses and Health Professionals / American Federation of Teachers believes that comprehensive reform must be undertaken and a system for national health care must emerge from that reform and therefore endorses the third option which calls for replacement of the current financing system. At a minimum, or at least as an interim measure, we endorse expansion of Medicaid by eliminating those eligibility requirements that have allowed the 30 million or more Americans to "fall through the cracks" and find themselves without health insurance. We encourage national legislation that would mandate employers to subsidize, at least in part, the cost of health insurance for their employees so that they would then become eligible for health care.

But, in considering health care access for all Americans, it is imperative that we also consider both the cost and quality of the health care that all receive. It is inconceivable that we spend more money on health care than any other country and have some of the worst statistics to show for it. It is these considerations that prompt the Federation to offer the following suggestions for the Commission's consideration.

RECOMMENDATIONS:

*There should be universal access, with no financial or service barriers, provided through a national system of health care.

*There should be an all-out effort to track and evaluate the utilization of health care dollars to determine both the value of the dollars spent and to facilitate equitable distribution of those dollars.

*There should be a national minimum standard of care established that should provide not only for treatment of illness but also for health education and screening focused on disease prevention.

*There should be mechanisms in place that provide data on the cost effectiveness and quality of treatment protocols, and that data should be publicly disseminated.

*There should be more utilization of community and home-based care, when appropriate, to help reduce health care cost and to promote access to health care.

*There should be increased utilization of health care professionals and practitioners in the delivery of high-quality, affordable health care.

*There should be incentives for all health professionals to relocate to those areas where access problems are most severe.

Office of Government Relations
Fran Du Melle, Director
1726 M Street, N.W., Suite 902
Washington, D.C. 20036-4502
(202) 785-3355
FAX (202) 452-1805

AMERICAN LUNG ASSOCIATION®
The Christmas Seal People®

STATEMENT OF THE

AMERICAN LUNG ASSOCIATION AND AMERICAN THORACIC SOCIETY

to the

United States Bipartisan Commission
on Comprehensive Health Care
The Pepper Commission

SUBJECT: Comprehensive care for Chronic Lung Disease

November 1, 1989

UNITED STATES BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE
THE PEPPER COMMISSION
TESTIMONY BY
AMERICAN LUNG ASSOCIATION/AMERICAN THORACIC SOCIETY

Chronic lung disease is a major health problem afflicting an estimated 24.4 million Americans. To maintain optimal functioning, patients with chronic lung disease require a wide range of health-related services. Medical treatment is primary but only one aspect of a comprehensive program for long-term care for patients with chronic lung disease.

In order for the Pepper Commission to carry out its mission of addressing and making recommendations regarding health policy programs needed to assure the availability of comprehensive long-term care for the elderly and disabled, the American Lung Association and its medical section the American Thoracic Society believe that consideration must include care and services for the range of chronic diseases, specifically chronic lung disease. The material presented will examine three aspects of chronic lung disease: (1) the prevalence rates and trends; (2) data on the economic impact data on the health care system caused by chronic lung disease; and, (3) the essential elements for providing comprehensive care for the patient with chronic lung disease.

DEFINITIONS:

Chronic lung disease as used throughout the text of this testimony includes chronic obstructive pulmonary disease (COPD) and asthma. Three disorders are incorporated in COPD: emphysema, and chronic bronchitis. COPD is defined as a disorder characterized by abnormal tests of expiratory flow that do not change markedly over periods of several months of observation. The airflow obstruction may be structural or functional. Specific causes of airflow obstruction such as localized disease of the upper airways, bronchiectasis, and cystic fibrosis are excluded.

Asthma is defined as a clinical syndrome characterized by increased responsiveness of the tracheobronchial tree to a variety of stimuli. The major symptoms of asthma are paroxysms of dyspnea, wheezing, and cough, which may vary from mild and almost undetectable to severe and unremitting (status asthmaticus). The primary physiological manifestation of this hyperresponsiveness is variable airways obstruction.

CHRONIC LUNG DISEASE: PREVALENCE RATES AND TRENDS

The prevalence of chronic lung disease varies with age. Asthma prevalence is reported to be highest in children less than 18 - prevalence is reported to be 52.5 per 1,000 persons in this population. The population over age 65 experience the second highest prevalence -- 38.6 per 1,000 persons. In 1987 there were 9.6 million asthmatics of all ages in the United States.

The prevalence of chronic bronchitis is highest in those over 65, when 75.9 persons per 1,000 are affected. The prevalence of emphysema increases steeply with age, affecting 17 people per 1,000 in the 45 to 64 year-old age group and more than doubling to 42 per 1,000 after age 65.

The prevalence of chronic lung disease will increase in magnitude because of the aging population and the resultant increase in the potential reservoir of symptomatic disease.

Smoking remains the single-most effective preventive measure to reducing the prevalence of chronic lung disease as well as other chronic diseases straining the health care system. The Pepper Commission is urged to emphasize smoking reduction as a critical component to decreasing disease prevalence.

Pneumonia and influenza, although not considered chronic lung diseases, cause grave illness and loss of life. Each flu season these diseases unnecessarily impact on the most vulnerable -- the elderly and the chronically ill -- and can easily be prevented by immunizations.

The U.S. population will grow substantially older, with the median age increasing from 30.3 in 1981 to 36.3 in 2000 and 41.6 in 2050. The proportion of people with health problems, including chronic lung disease increases with age, and, as a group, the elderly are more likely than the young to suffer from multiple chronic and often disabling diseases. Eighty percent of our elderly have one or more chronic conditions, and their medical treatment accounts for about 31% of the nation's health care expenditures.

CHRONIC LUNG DISEASE: IMPACT ON THE HEALTH CARE SYSTEM

In 1987 chronic lung diseases were responsible for 9% of total hospital discharges. Over 810,000 discharges in 1987 were shown to be related to chronic obstructive pulmonary disease (COPD) and its allied conditions. The average length of stay for COPD is 6.0 days and ranges from 4.6 to 9.5 days, depending on the specific disease.

Direct and indirect costs for the chronic lung disease patient constitute a heavy economic burden on the health care system and consumer. Direct health care expenditures for COPD was $4.6 billion in 1988. Hospital care for patients suffering from chronic lung disease reached an estimated $3.15 billion in 1985. Of this total expenditure, ancillary costs are estimated at $1,423 billion. The cost incurred for specific medical services such as laboratory work, X-ray, medicine, anesthesia can be derived as a percentage of the total expenditure for ancillary costs.

For chronic lung disease patients inpatient hospital laboratory services, which may include blood count and analysis, urinalysis, bacteriological studies and sputum cytology, are estimated to have cost $293.3 million in 1985. Similarly, inpatient radiological services reached an estimated $107.2 million, medications $116.7 million, and costs for operating room and anesthesia expenses $19.7 million. Inference about the costs of services associated with medical care in other health care settings (such as nursing home and at-home care, as well as clinical, laboratory and radiological medical services) can be made from the costs incurred from these general hospital services.

In addition, direct costs (derived from morbidity and mortality) for chronic lung disease are also significant in calculating a complete estimation of continuing care costs. In 1988 indirect costs for chronic lung disease totaled $5.6 billion.

Not included in the indirect expenditure figures are the elements of comprehensive care these patients require; such as counseling, rehabilitation and family and patient education. The costs associated with these services, plus the loss to the economy in lost work days of a productive person, has been estimated to be $3.85 billion. These figures have important implications in the development of a system to provide care comprehensive care to patients with chronic lung disease. COPD is one of the most rapidly rising causes of death in the United States. From 1979 to 1987 the age adjusted death rate attributed to COPD rose 28.1 percent -- this is the largest increase seen among the leading causes of death.

COMPREHENSIVE CARE OF CHRONIC LUNG DISEASE

In order to maintain optimal functioning in the face of a disabling condition, patients with chronic lung disease require a wide range of health-related services. Medical treatment is primary but only one component of a comprehensive care program. Attention must also be paid to the social and economic needs of these patients and their families. Provision of the range of services requires the input of many professional and allied health personnel and the availability of a variety of health care facilities. Adequate funding for each component is essential. A comprehensive plan of care must provide for the coordination of each of these services into a unified program.

An emphasis on medical services to include early detection to prevent unnecessary illness and disability from lung disease should be a focus of health policy. However, there is currently no effective screening for chronic lung disease. Early detection and comprehensive care of symptomatic persons are important to allow the patient to maintain functional ability even as disease progresses; this is important as it has an impact on the need for repeated hospitalizations and increased costs for care. Initial evaluation of the patient should include a comprehensive medical evaluation (complete medical history and the full range of diagnostic techniques) and a psychosocial evaluation.

In terms of physician care usually, the patient's family physician makes a tentative diagnosis of chronic lung disease. In most instances a consultation with a pulmonary specialist is suggested. In some cases, because of the nature of the extent of the patient's disease, referral to a pulmonary specialist is necessary or desireable.

A variety of oral, parenteral, and aerosolized medications are required to treat chronic pulmonary disease. In addition, some patients require oxygen and durable medical equipment, such as nebulizers, humidifiers, suctioning equipment and mechanical ventilators.

Given the nature of chronic lung disease, long-term care protection is the central and most crucial element of health care for these victims.

For the patient with chronic lung disease to obtain the maximum benefits of medical care, three important preventative measures must be undertaken: eliminating smoking by and around the patient, immunizing against influenza and pneumonia, and reducing other environmental and occupational hazards.

Comprehensive care should also include patient and family education, respiratory care (including bronchial hygiene and physical conditioning), pulmonary rehabilitation, adequate nutritional support, and emergency and acute medical care.

CHRONIC LUNG DISEASE AND THE HEALTH CARE SYSTEM

It is well established that up to 38 million Americans are not covered by any form of health insurance. Millions more are covered with inadequate insurance. The human tragedy, the personal pain, that results from such a haphazard health care system, is immeasurable. The effect on those with chronic lung disease is devastating for both the patient and family.

People at high risk and with preliminary signs of lung disease are the best candidates for treatment. Intervention early on in the disease process can have a significant positive impact on the patient and should be emphasized along with preventive care strategies. Unfortunately, those with chronic lung disease who are without basic health care coverage, or cannot obtain private health insurance coverage due to their illness, do not get the medical attention they need. When they do get in to the health care system it is often too late to be most effective and least expensive.

For those with inadequate health insurance coverage there are gaps and inequities related to the types of services covered and the duration of the coverage. Little uniformity of coverage exists. Many private and governmental insurance programs provide coverage for only acute care, for example, hospitalization and limited post-hospital care. Patients with chronic lung disease require continuous care in order to prevent recurrent acute exacerbations.

This care must be augmented by support care, such as household assistance and self-management education programs, in order to ensure that the patient maintains an optimal level of functioning. Many health plans require that the patient be confined to his or her residence or health related facility in order to qualify for coverage. Such requirements adversely affect patients with lung disease. Decreased activity levels not only increases the patient's dependence on others but can also increase the incidence of complications thus, resulting in further deterioration of both physiological and psychological states that ultimately inflates the cost of providing health care coverage.

CONCLUSIONS AND RECOMMENDATIONS:

The consequences of chronic lung disease are felt at the individual level as well as throughout the health care system. They are both personal and economic. Chronic lung disease is a major public health problem that demands attention in the development of a comprehensive long-term health care policy for the United States. With the population aging, chronic lung disease will increase as a burden for both public policy makers and health care professionals. In order to reduce the extent of the problem of chronic lung disease, the American Lung Association/American

Thoracic Society **recommends** the development of a comprehensive health care policy that:

1. That takes into consideration their physical, psychosocial, and economic needs;
2. Provides for a full range of medical services, including medical and psychosocial evaluation, and delivery of medical care from initial diagnosis through rehabilitation when appropriate;
3. Provides universal access to health care;
4. Emphasizes preventive measures such as comprehensive immunization for pneumonia and influenza as well as smoking control and cessation;
5. Sets standards related to the diagnosis and treatment of chronic lung disease to establish acceptable criteria throughout the entire health care system;
6. Modifies the current reimbursement system to allow communities to provide the best, highest-quality care in the most appropriate setting possible;
7. Encourages broad-based public and private support for research and training programs that will produce competent researchers and practitioners who will maintain the highest quality of medical care.

UNUM.

UNUM Life
Insurance Company
2211 Congress Street
Portland, Maine 04122
207 770-2211

October 20, 1989

Edward F. Howard
General Counsel
The Pepper Commission
United States Bipartisan Commission
on Comprehensive Health Care
140 Cannon House Office Building
Washington, DC 20515

Dear Mr. Howard:

I am pleased to offer the attached comments of UNUM Life Insurance Company of Portland, Maine, to the Pepper Commission on the issue of "Options in Long Term Care." Please consider this letter as a summary of UNUM's comments.

By way of introduction, UNUM Life Insurance Company is the nation's leading provider of group long term disability insurance and is also a major provider of employee benefits, individual disability insurance, and retirement income products.

Recently, UNUM introduced a family of long term care insurance (LTC) products covering employee groups and specifically defined elderly groups, including residents of retirement housing. Utilizing our knowledge and expertise in disability income protection coverage, we have developed long term care insurance products based solely on the level of disability of the insured. In other words, we pay benefits based on the insured's cognitive impairment or his/her inability to function in certain activities of daily living. Unlike medical expense reimbursement LTC insurance typically offered on the market today, our unique and flexible product pays an indemnity benefit to an insured either in a nursing home or at home (home also includes a relative's home, assisted living, CCRC, etc.). Benefits are triggered by the level of disability and are not strictly tied to the cost of specific services rendered. Our innovative product permits the insured the flexibility of using the benefits for whatever services best fit his/her needs. Many times, those are services not commonly reimbursed by other insurers or by government programs.

In addition, we offer care management as a special feature of our retirement housing long term care product, thus assuring that the insured's ability to function is objectively assessed and that he/she receives services in the most appropriate setting. An indication of how well UNUM's long term care products for residents of retirement housing meet the needs of the consumer is the recent endorsement of this product by the American Association of Homes for the Aging (AAHA), a national organization representing nonprofit providers of health, housing, continuing care retirement programs, and community services to over 500,000 persons. As you know, AAHA recently testified at the Commission's October 5th hearing.

My point in explaining our products is to highlight three issues for the Commission:

1. There is an important role for private insurance in helping to resolve the nation's serious long term care problems. Only through a private-public partnership can the nation address long term care.

2. Private long term care insurance is evolving, and there are unique products such as ours being developed. Any federal standards or tax incentives with respect to private long term care insurance must recognize a wide and growing variety of approaches to providing such insurance and must provide a level playing field on which competing LTC products can continue to evolve in response to market pressures.

3. Growth of the private long term care insurance market will only occur with a fair and equitable tax incentive program.

The primary point of our attached comments is that as the federal government develops its process for addressing the long term care needs of American citizens, it should consider and include approaches such as UNUM's in establishing appropriate public policy.

We appreciate the opportunity to provide comments to the Commission, and I am available for any questions you might have concerning our comments.

Sincerely,

David H Brenerman

David H. Brenerman
Manager, Government Relations

DHB:wcm

cc: Christine Williams, c/o U.S. Senator George Mitchell
Representative Olympia Snowe
Representative Joseph Brennan
Senator William Cohen
Susan Van Gelder, HIAA
Steve Kraus, ACLI
Julie Spiezio, ACLI

2081

Testimony by UNUM Life Insurance Company
on "Options in Long Term Care"
for the Pepper Commission
October 18, 1989

UNUM Life Insurance Company is pleased to offer its views to the Pepper Commission on the issue of "Options in Long Term Care." Our nation faces a very serious and very expensive social problem. Recent medical and societal advances have provided a mixed blessing. As a population we are living longer; as we live longer, we face a greater possibility of becoming disabled and, consequently, a greater likelihood that we will be unable to afford the cost of such a disability. How will our parents afford to take care of themselves as they grow older; and how will we and our children meet the costs of long term care when it becomes necessary?

Many people wrongly believe that Medicare, Medicaid, or traditional health care plans will cover the expenses of assisted or dependent living at any age. In most cases, however, bills are paid from family savings -- a finite resource generally not designed to handle the potentially devastating cost of long term care. Clearly, there exists a need for a means to provide affordable, consistent, and high quality care for our elderly and disabled. UNUM believes that a combination of private long term care insurance and public programs for those who cannot afford insurance will best address this problem. Our testimony will focus on how the federal government can work in partnership with the insurance industry to encourage the provision of private long term care insurance to the citizens of this nation; suffice it to say that we see the federal government's role in providing long term care as limited to a social insurance program for those persons who do not qualify for Medicaid, and who cannot afford long term care insurance in the private market. In addition, our testimony will emphasize the unique nature of UNUM's own long term care insurance products and how they meet the need for long term care in this country.

By way of introduction, UNUM Life Insurance Company is the nation's leading provider of group long term disability insurance and is also a major provider of employee benefits, individual disability insurance, and retirement income products.

Recently, UNUM introduced a family of long term care insurance products covering employee groups and specifically defined elderly groups, including residents of retirement housing. Utilizing our knowledge, experience, and expertise in disability income protection coverage, we have developed long term care insurance products based solely on the level of disability of the insured. In other words, we pay benefits based on the insured's cognitive impairment or inability to function in certain activities of daily living. Unlike medical expense reimbursement LTC insurance typically offered on the market today, our unique and flexible product pays an indemnity benefit to the insured either in a nursing home or at home (home also includes a relative's home, assisted living, CCRC, etc.). Benefits are triggered by the level of disability and are not strictly tied to the cost of specific services rendered. Our innovative product permits the insured the flexibility of using the benefits for whatever services best meet his/her needs. Many times, those are services not commonly reimbursed by other insurers or by government programs.

In addition, as a unique and special feature of our retirement housing long term care product, we offer care management which assures that the insured's ability to function is objectively assessed and that he/she receives services in the most appropriate setting.

An indication of how well UNUM's long term care product for residents of retirement housing meets the needs of the consumer is the recent endorsement of this product by the American Association of Homes for the Aging (AAHA), a national organization representing nonprofit providers of health, housing, continuing care retirement programs, and community services to over 500,000 persons.

My point in explaining our products is to highlight three issues for the Commission.

1. Public-Private Partnership: There is an important role for private insurance in helping to resolve the nation's serious long term care problems. I need not discuss all the demographics of the long term care crisis. The Commission has already received that information from a number of sources. In addition, representatives of the insurance industry and business community (HIAA, ACLI, and others) have testified that this long term care crisis can be addressed only by a partnership between the public and private sectors. We endorse these comments.

   Both budgetary and social policy considerations compel the conclusion that the federal government alone cannot finance this gap in services for elderly and disabled individuals. The responsibility for providing long term care assistance is that of all of us -- individuals, families, the private sector and government. We believe that the federal government can most efficiently use available public and private long term care dollars by encouraging those who can afford it to protect themselves through the purchase of private long term care insurance. The tremendous increases in the cost of nursing home care demonstrate quite conclusively that the federal government could not afford the enormous cost of a federal program covering all Americans needing long term care services; therefore, government should focus scarce resources on those who cannot afford to provide for their own long term care.

2. Flexibility: Insurers are developing innovative long term care products which attempt to address consumer demands in an affordable manner. Because private long term care insurance is evolving, and there are unique products such as ours being developed every day, it is important for

federal policymakers, in any standards they may impose, to appropriately balance flexibility with consumer protection. Strict regulation in the name of consumer protection may not ultimately benefit consumers if it stifles insurers from providing the types of LTC insurance consumers may ultimately want and, most importantly, can afford.

To that end, we urge that any federal standards or tax incentives recognize and encourage a variety of approaches to private long term care insurance. Simply put, private insurers need a level playing field on which to compete. Governmental standards and tax incentives must treat each long term care approach equitably. In developing its recommendations with respect to private long term care insurance, the Commission should not have a narrow focus based on what yesterday's or today's long term care policies look like. Federal policies must be flexible enough so that private insurers can develop new products that meet the long term care needs of our citizens.

If state regulators had not been willing to be flexible and to use their discretionary authority, products like those offered by UNUM would not be in the market today. Through UNUM's long term care products, insureds can have the flexibility to purchase the services that traditional long term care policies would not pay for. A recent Public Broadcasting System (PBS) special program on long term care, hosted by Walter Cronkite, pointed out the types of problems that families of disabled individuals have in paying for certain types of long term care services (i.e. respite care, various forms of home care and home chore services, medications and prosthetic devices, and loss of income by family members who must take time from work to care for disabled relatives). That broadcast has made it clear to us that we are on the right track by providing our insureds with the funding and flexibility to buy the services they need.

We applaud the National Association of Insurance Commissioners (NAIC) for attempting to fairly regulate long term care insurance from both the consumer and insurer's perspectives and for continually adjusting the Long Term Care Model Act and Regulation to address emerging issues; however, the fact is that the current NAIC Models focus on long term care insurance as a) insurance sold only to the elderly, and b) sold only on a medical expense reimbursement basis. This is so because, in its beginning stages, LTC insurance was sold primarily to the elderly and provided basically nursing home expense coverage. Neither is true any longer, and the NAIC is beginning to recognize that fact.

Because UNUM has a policy based on loss of function rather than medical reimbursement, we are attempting to amend the NAIC Model definition of long term care insurance to recognize disability based long term care products. We want to make certain that regulators specifically recognize in their Model law that such products exist and are beneficial. Otherwise we must ask the regulators in each state to interpret the Model to apply to our policies (a task we have completed successfully in 43 states to date). We offer our amendment to the NAIC Model for the Pepper Commission's consideration. If the Commission intends to recommend a definition of long term care insurance as part of its report to Congress, our proposal would be a "state of the art" definition. We also offer this definition as part of the record of the Commission's work so that any member of Congress submitting long term care legislation might see it and use it.

NAIC Model Long Term Care Act (as proposed to be amended):

Section 4. Definitions

Unless the context requires otherwise, the definitions in this section apply through this Act.

a. "Long Term Care Insurance" means any insurance policy or rider advertised, marketed, offered, or designed to provide coverage for not less than 12 consecutive months for each covered person on an expense incurred, indemnity, prepaid or other basis; for one or more necessary or medically necessary diagnostic, preventive, therapeutic, rehabilitative, maintenance or personal care services, provided in a setting other than an acute care unit of a hospital. Such term includes group and individual annuities and life insurance policies or riders which provide directly or would supplement long term care insurance. SUCH TERM ALSO INCLUDES A LONG TERM CARE INSURANCE POLICY PROVIDING COVERAGE FOR COGNITIVE IMPAIRMENT OR THE LOSS OF FUNCTIONAL CAPACITY. Long term care insurance may be issued by insurers; fraternal benefit societies; nonprofit health, hospital, medical service corporations; prepaid health plans; health maintenance organizations or any similar organization to the extent they are otherwise authorized to issue life or health insurance. Long term care insurance shall not include any insurance policy which is offered primarily to provide basic Medicare supplement coverage, basic hospital

> expense coverage, basic medical/surgical expense coverage, hospital confinement indemnity coverage, major medical expense coverage, disability income OR RELATED ASSET protection coverage, specified disease or specified accident coverage, or limited benefit health coverage.

The final point we would like to make regarding flexibility is that any guidelines developed by the federal government on long term care insurance should be flexible and permit LTC policies that pay directly for a variety of long term care services or pay indirectly for services by providing the insured with funds that can be used for services that are most appropriate for him/her.

3. Tax treatment of long term care products: UNUM sees two primary roles for the public sector in addressing the financing of long term care services to our citizens: a) providing long term care to persons unable to afford private insurance and who do not qualify for Medicaid; and b) encouraging private insurance for as many persons, both young and old, as possible. The most effective method for encouraging the sale and purchase of long term care insurance is through an equitable tax incentive program which stimulates the private market and clarifies the tax status of long term care premiums and benefits. Such tax policies should also encourage a variety of socially desirable approaches to private long term care insurance, recognizing that there are innovative and unique products being developed. Private long term care insurance has made marked advances in the last few years. However a financial commitment from the federal government, in the form of favorable tax policy, will be needed to encourage further development of private long term care insurance, and to encourage its purchase by consumers.

   Currently the status of long term care insurance with respect to its tax treatment is unclear. To encourage the growth of private insurance, the federal government needs to take the following actions with respect to the tax treatment of long term care insurance:

   - Long term care benefits should be excluded from the income of the insured, similar to the treatment of health insurance benefits.

   - Premiums paid by an employer for long term care insurance for an employee should be excluded from the income of the insured and should be deductible for the employer, just as health insurance premiums are deductible for employers.

- Some form of tax credit program should be developed to encourage individuals and employers to purchase long term care policies.

- Any tax program must provide equitable treatment for different approaches: those providing benefits to individuals through medical expense reimbursement and those providing benefits based on the loss of functional capacity of the insured.

The cost of providing such favorable tax treatment to long term care insurance would be much less of a burden on the federal budget than would a comprehensive federal long term care program. In addition, the public would support such a tax program for long term care because we have all either been touched by the need for long term care in our own families or will be affected by such long term care needs in the future.

Conclusion: As the Pepper Commission considers its recommendations to Congress on how to address long term care and the financing of long term care, UNUM urges consideration of three key points: 1) That the long term care crisis cannot be solved by the federal government alone. In partnership with individuals, private insurance companies, and families, the federal government can adopt a comprehensive program to address a very vital and far reaching issue. 2) Whatever action the Federal government takes with respect to private long term care insurance, it must recognize the developing market. In doing so, it must be as flexible as possible in permitting a number of different types of private long term care insurance approaches, including innovative products such as UNUM's. 3) The best and most cost efficient way to encourage the purchase of long term care insurance, to encourage the development of innovative products, and to broaden the availability of private long term care insurance is through favorable tax treatment of benefits and premiums in both groups and individual policies.

We appreciate the opportunity to present UNUM's views on the long term care crisis. We look forward to working with the Commission and with Congress to develop legislation that will address the problem as effectively as possible.

Respectfully submitted,

David H. Brenerman
Manager, Government Relations
UNUM Life Insurance Company

DHB:wcm

ANNA
American Nephrology Nurses' Association

November 15, 1989

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Senator John D. Rockefeller, IV
Chairperson
Bipartisan Commission Comprehensive Health Care
140 Cannon House Office Building
Washington, DC 20515

Dear Senator Rockefeller:

The American Nephrology Nurses' Association (ANNA) is pleased to respond to the Bipartisan Commission on Comprehensive Health Care, the Pepper Commission, and provide information to assist the members in their mission as directed by the Catastrophic Coverage Act. It is to Rep. Claude Pepper's credit that he accepted the challenge to address this sensitive, but extremely important area. It is unfortunate that he will not see his efforts come to fruition.

Enclosed is a more detailed response to our earlier correspondence to the committee. We remain concerned that any national long-term health care agenda should carefully examine the history and experience of the end stage renal disease (ESRD) program. This first and only catastrophic illness funded through Medicare in 1973, can provide a perspective not realized in any other health care area. Since 1973 the ESRD program has been successful in assuring access to quality care and treatment in the face of declining reimbursement. Unfortunately, it has been highly criticized for being too costly. However, a more detailed analysis of the program unquestionably proves that costs are associated to the unexpected number of patients on dialysis, whereas, the per capita cost has decreased since 1973. Certainly an understanding of the overall ESRD program experience, including successes and limitations, would serve to enhance the Commission's final recommendations.

We are hopeful that this exchange of views and information pertaining to the U.S. health care delivery system will benefit the patient/family/consumer for years to come. If you have any questions regarding this document or want to discuss it with a Board member, please feel free to call Sally Burrows-Hudson, MSN, RN, CNN, President-Elect (408-732-1893). You may also reach Sally through the national office.

We look forward to receiving the Commission's final report.

Sincerely,

Evelyn Butera

Evelyn Butera, MS, RN, CNN
President

lpf

ANNA National Office/North Woodbury Road/Box 56, Pitman, NJ 08071/609-589-2187/FAX 609-589-7463

ANNA
American Nephrology Nurses' Association

Summary of Recommendations to the Pepper Commission

- Examine, in depth, the experience of the ESRD program. As the first and only catastrophic illness funded by Medicare, it can provide the commission a perspective not found in any other area of health care;
- Study and incorporate the humanistic and chronic illness perspective into the Commission's final recommendations;
- Develop a coordinated health care delivery system, ensuring that patient interest and opportunities are realized through patient, professional, and economic incentives;
- Develop a clear description of what is to be purchased by Medicare;
- Identify and use data that accurately describe the relationships of reimbursement, access to services, quality of care, and morbidity and mortality;
- Invest in ongoing monitoring and evaluation when dealing with the more prolonged and all-inclusive effects of a chronic condition;
- Develop and implement an outcomes management program to assist patients, payors, and professionals in making rational health care decisions; and
- More adequately share the costs of the program with the private sector by removing the 12-month limitation of EGHB as the primary payor.

ANNA National Office/North Woodbury Road/Box 56, Pitman, NJ 08071/609-589-2187

ANNA
American Nephrology Nurses' Association

I. Introduction

Nephrology Nursing: An overview

ANNA is a non-profit, professional organization concerned with promoting high quality care for people with actual or potential impairment of renal function. Our membership of over 5,000 registered nurses is primarily involved in conservative management, peritoneal dialysis, hemodialysis, and transplantation.

The specialty of nephrology nursing has evolved in response to increasingly complex knowledge, technology, and required clinical expertise. The growth of our specialty has paralleled that of an expanding and recognized patient population directly attributable to clinical and technological advances as well as federal and state financing. Changes in our society over the past 10 years have also impacted on nephrology nursing. The sociopolitical regulations and reimbursement changes have affected how and where patients receive care, thus altering the role and responsibilities of the nephrology nurse and other members of the nephrology health care team.

As a specialty within nursing we continuously incorporate the changes and developments affecting our profession as a whole. We are committed to assisting our practitioners in protecting the future of quality of care through education, research and a strong clinical practice base.

ANNA National Office/North Woodbury Road/Box 56, Pitman, NJ 08071/609-589-2187

ESRD Program: An overview

In 1973, end stage renal disease became the first and only catastrophic illness for which the government paid treatment costs for nearly all persons, both under and over the age of 65. The decision to implement the end stage renal disease (ESRD) program was founded on humanitarian motives. The congressional intent at that time was to provide access to life-saving therapy for all who needed it, where costs of treatment were beyond the means of practically all individuals.

This program has been successful in meeting its stated goals of providing access to life-sustaining renal replacement therapy. Today, through the ESRD program more than 100,000 people are being supported by chronic dialysis or transplantation therapy. Virtually no one is denied access to dialysis because of regulated distribution of services throughout the country. Additionally, the quality of service has been high due to the mechanisms for oversight, mandated since the program's inception.

During the late 1960's and early '70's, the majority of the patients undergoing ESRD treatment were young to middle age and middle class with no other illnesses. By the late 70's, patients were considerably older, had complicating diseases such as diabetes, and were increasingly poor and from minority groups.

Technological advances in both dialysis and transplantation enable practitioners to provide ESRD patients high quality renal replacement therapy. The technological changes occuring over the last 20 years includes: equipment and membrane control technology, surgical techniques, pharmacology, and models for therapy adequacy monitoring.

Renal replacement technology, while initially influenced by federal and state financial support, has been affected by the more recent cost containment efforts: reuse of disposables has become "common practice", the use of sophisticated equipment to shorten the dialysis treatment time, and the encouragement of home/self care via peritoneal dailysis. Although technological advances continue to occur, the pace is considerably slower. Still, much thought is being given to developing an inplantable artificial kidney, simulating as close to normal renal function as possible.

The experience of the ESRD program should serve as a model for future government efforts in supporting long term care. The ESRD program has been successful in assuring access to quality treatment and care, as well as demonstrating cost efficiencies since its inception. Certainly a more indepth review of financial, clinical/technological, and regulatory history of the ESRD program is mandatory for the commission.

The material that follows describes our concerns with the current health care delivery system, its financing, and quality assurance. Background and recommendations are provided to assure a meaningful dialog.

II. Health Care Delivery System

Backgound

The ESRD program, as originally conceived, was disease-specific focused. The patient population in the early 70's were young to middle aged, with no complicating diseases or ilnesses. Renal replacement therapy, while not curing the underlying renal disease, certainly provided a method to sustain life.

The changes in demographics and clinical picture have altered the quantity and quality of care required to meet the patients' multiple health care needs. Although the focus of the program is disease specific, the actual needs of the patients are individualized holistic responses to their chronic illness(es), of which ESRD is only one. The ESRD health care delivery system was not designed with this perspective in mind and as a result did/does not meet individual patient need.

Chronic Illness

Figure 1 demonstrates how a chronic illness encompasses and affects every dimension of the individual: physiological, social, psychological, and cultural. While renal replacement therapy can successfully sustain life and, when used in conjunction with other medical technology can relieve physiological symptoms, it cannot cure or control all other individual humanistic responses to the chronic illness(es) and treatment regimen. Thus, we are faced with a more complex patient than originally imagined and the health care delivery system as it currently exists has been able to only partially respond.

Further, the chronically ill person tends to utilize a wide variety and number of health care agencies or institutions and related professionals. Figure 2 demonstrates this complex system.

The all encompassing chronic illness exposing significant human needs and the obvious utilization of a variety of health care settings and providers demonstrates that a disease focused, acute and episodic health care model fails the patient and family. The patient is responsible for putting together the pieces of the health care delivery system so that it makes sense and meets required health care needs. From the perspective of a chronically ill individual, this system is not only overwhelming, but frustrating and exhausting as well. There is a decided lack of coordination and communication resulting in significant inefficiencies, duplication and fragmentation.

We believe this same duplication and fragmentation is found in other areas of health care as well. Those patient populations most certainly include the frail and chronically disabled; many over the age of 85. Others include the developmentally disabled, physically handicapped, and mentally handicapped. Others are those with long-term, medically complex problems requiring multifaceted, costly care; including those who are dependent upon technology (such as ESRD), high risk infants, individuals with AIDS, and transplant patients.

Recommendation

It is our strong recommendation that the commission view its task at hand from a humanistic and chronic illness perspective. What is required is a dedicated system where care can become streamlined and more efficient, focusing on all dimensions of the human.

This dedicated system may be best described as managed care. The managed care concept incorporates risk assessment and integrated interdisciplinary long-term care planning with coordination of treatment and care, and outcome monitoring.

The primary goal of a coordinated health care system is to assure that each patient receives the best possible health care services and that the patient and family are fully informed of, and supported through treatment options. The secondary goal is to reduce the cost of providing health care without compromising quality. This is acheived by promoting the appropriate use of resources to maximize recovery and minimize complications.

A managed care delivery system brings into harmony the professional, patient, and economic incentives in a manner helping to ensure that patient interests and opportunities are realized. Patients experience unrestricted medically appropriate access to all treatment therapy options. This system will also renew provider interest in patient education, treatment planning, preventive care, and rehabilitation. New technology can be carefully assessed for its potential effect on quality and cost to assure maximum benefit and, of course, limited risk to the patient.

Managed care can best achieve the following objectives:

- assure high quality care through active, ongoing coordination and continuity of services;
- use of specialized rehabilitation services to maximize recovery;
- recognize and report potential complications as well as recommend and coordinate early intervention;
- facilitate informed decision making by providing information to patients and families assuring interdisciplinary communication;
- assure judicious use of health care resources through the use of recognized alternatives to traditional care and preventive interventions;
- allocate and monitor health care benefit dollars for optimum use over the duration of the illness;
- decrease disability time by closely monitoring recovery; and
- minimize future illness and injuries through health maintainence and prevention promotion.

Nurses are particularly suited to coordinate a managed care delivery system. Nursing focuses on creating the physiological, psychological, and sociocultural environment in which the patient can gain or maintain health. These characteristics, unique to nursing, enable the nurse to address the issues of allocation of resources, effectiveness of care, and cost containment. We strongly recommend that nursing coordinate the managed care delivery system as well as serve as an active clinical practioner in a primary care giver role.

III. Finance

Background

The present reimbursement system drives our health care delivery system. As a result, our patients are inadequately and inefficiently served by a fragmented health care delivery system. The current payment system rewards over-utilization, fragments provider efforts and does not offer incentives to achieve positive clinical outcomes.

The political process has forced the ESRD program into a state of perpetual controversy. The program has been highly criticized for its climbing consumption of the health care dollar. Gornick points out, however, that the ESRD program experienced a 63% increase in expenditures from 1974 - 1983 compared to a 280% overall increase in Medicare. What is commonly not known or significantly understated is that reimbursement for dialysis treatments has decreased since 1974; not keeping pace with inflation or rising costs of new tecnhnology, labor and support services. The dialysis program has been capped since its inception.

Funding has been set on a year to year basis, established with patient population data three to five years old and with formulas designed to meet budgetary requirements. Further, the rates fail to consider the increase in number of severely ill and/or complex patients treated in facilities.

Over the years, nephrology nurses and other members of the nephrology health care team have supplied and offered services beyond the traditional "dialysis treatment" within the dialysis unit and without expectations for further reimbursement. Today, services such as dressing changes, psychological or family support counselling, patient education, self care training, health maintenance programs, and other clinical support, are no longer offered by dialysis facilities. The resources required to continue this practice in the dialysis unit no longer exist. Where Medicare may have saved a few dollars by decreasing reimbursement for dialysis, the costs for these services have simply shifted to emergency rooms, hospitals, home health agencies and or physician offices.

We believe other areas of health care have experienced this fragmented reimbursement system, as well. The prospective payment system has decreased hospitial stays and avoided unnecessary admissions. Although this has been a boon to home health care programming and outpatient departments, hospitials find themselves treating sicker patients while the less complicated ones are treated in the outpatient settings. Thus, hospitals are finding that after initial cost containment efforts, they are still cash flow poor and lack capital for long term maintenance or growth. Many of the better managed community hospitals are either contemplating closing altogether or, at the very least, downsizing. Downsizing or the eliminations of services has had and will continue to have a negative impact on the health care consumer. Hospitals that do not turn a profit cannot improve facilities and services. And, as the commission is aware, hospitals need some financial leeway to provide charity care to indigent patients.

Policy decisions driven by budget considerations and heavily influenced by the highly charged political environment have been narrowly targeted on selective providers and have delt almost exclusively with the program objective of cost containment. The use of reimbursement caps, limited incentives and competition has ignored other fundamentally important issues: quality assurance, continuity of care, and data that would allow careful analysis of the overall delivery system.

Health care policy and financing and regulation problems have been attacked in a piece meal fashion. Fragmented reimbursement policies and continuing payment modifications, will not control the continuous rise in per capita cost; each provider subset will strive to maximize reimbursement. There is a serious need for a strong sense of direction and vision for the future.

Recommendation

First, we strongly recommend that the government with external professional input develop a clear description of what is being purchased by Medicare. There is a decided lack of understanding of what is required to care for an individual who is chronically ill.

There is a need for integrated financial incentives to control costs. Each provider should have a major stake, not only in cost, but also the quality of services in that every chronically ill person/patient is a long-term system user.

Further, we support the need for data about the relationships among reimbursement, access to services, quality of care, and morbidity and mortality experience of patients. HCFA must obtain this information to establish a reimbursement system that balances the goals of quality, access, and efficiency. This type of evaluation process, conducted annually using current data, will contribute information that encourages long-range direction and vision for the Medicare program.

IV. Quality Assurance

Background

As previously pointed out, the reimbursement mechanism drives our health care delivery system leading to inefficiencies, duplication, and fragmentation. This affects quality of care and limits our ability to conduct comprehensive quality assurance.

HCFA has attempted to control ESRD costs over the years by encouraging patient shifts to home dialysis and transplantation, establishing a target rate for dialysis treatments, implementing composite rate and rate reductions, shifting first year expenses to third party payers, and stimulating competition. All of these piecemeal measures were instituted without adequate outcome monitoring procedures.

When the final ESRD regulations were published, a formal consolidation of state and federal criteria was implemented including a mandate to the then Secretary of Health, Education, and Welfare to regulate health care provided to ESRD patients (PL-95-292). Recognizing that the monitoring and regulation of the care to these patients were considerably different than other medical review processes being undertaken, the DHEW proposed a unique and unusual approach in the organization of this medical review process.

The country was divided into 32 "networks", each functioning as a relatively autonomous unit and ultimately responsible to the Secretary. Each dialysis and transplant provider "belonged" (as members) to the network, making up its council and electing its medical review board. Today, restructuring of the system has left 17 networks with oversight responsibility for over 100,000 patients.

The federal charge to the network medical review boards was very much the same in 1976 as it is today; that is, 1) monitor the appropriateness and effectiveness of long term care, 2) perform medical case review and special studies, 3) assure referral to home dialysis and transplantation, and 4) encourage vocational rehabilitation.

While networks have been moderately effective, the focus of oversight (as required by federal legislation and regulation) has concentrated on the dialysis facility and treatment. Emphasizing once again, how quality of care review efforts are fragmented. Networks evaluate patient outcomes and care received in dialysis units only. We need to keep in mind the other numerous agencies and institutions that our patients utilize (refer to Figure 2); each impacting on the overall patient outcome. The networks are not authorized to conduct quality review in these other agencies. The very nature of chronic illness as described in previous sections mandates that we examine, through a comprehensive quality assurance process, care provided to the patient as a whole. This means all providers must assume responsibility for and participate in the QA process.

State surveyors also inspect dialysis facilities for compliance with state and federal regulations. The surveyors have simply done the best that can be expected. Many are totally unfamiliar with the ESRD program and treatment regimen, let alone chronic illness care. The surveys focus primarily on structural aspects and medical record documentation. Further, there have been significantly long intervals between inspections, the provider community has not been allowed input to the process, and in most cases, surveyors do not share information with the networks. The survey process has offered little educational opportunity to improve care provided to patients. This long standing government supported oversight program is out of date and out of sync with patient experiences, offering minimal protection to the public.

Recommendation

Medicare needs to make a significant investment in "follow-up" when dealing with the more prolonged and all inclusive effects of a chronic condition. Opportunities to improve care must be built directly into the complex health care delivery system. Adopting the "Theory of Continuous Improvement" as described by Berwick would provide the necessary environment to ensure high quality in Medicare health care delivery.

Further, and most importantly, we believe patients and their families must be included in the evaluation process. We support Paul Ellwood's recommended system of "outcomes management". That is, a system designed to help patients, payers, and providers make rational health care related choices. Dr. Ellwood stipulates that the following must be present:

- a common, patient understood language of health care outcomes;
- a national data base containing information and analysis on clinical, financial, and health outcomes that estimates as best we can the relationship between health outcomes and money;
- an opportunity for each decision maker to have access to the analyses that are relevant to the choices they must make.

Summary

When devising a national long-term health care agenda, we believe the commission should carefully examine the history and experience of the ESRD program. We further believe that a managed care delivery system would benefit the chronically ill patient in that it brings into balance the patient, professional, and economic incentives required for optimal clinical outcomes. And finally, we strongly support the need for investing in long-term comprehensive and integrated monitoring and evaluation of all program objectives.

Figure 1.

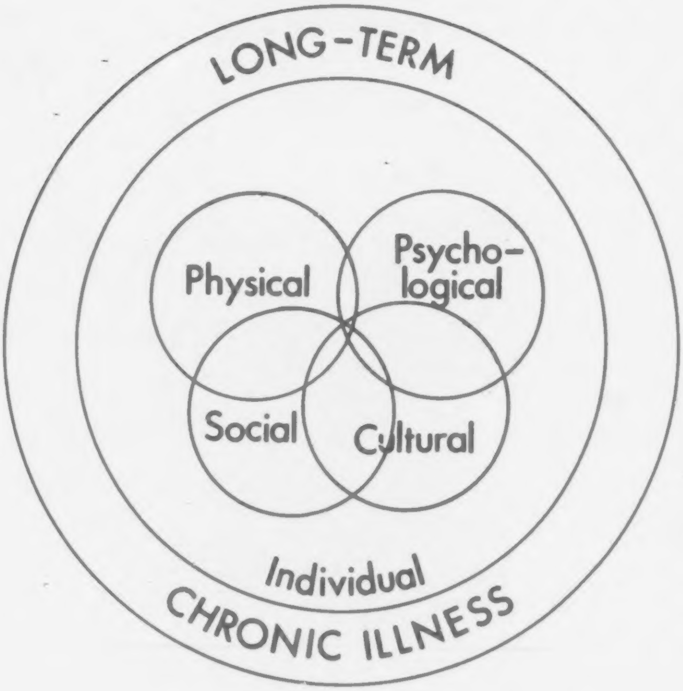
LONG-TERM
Physical
Psychological
Social
Cultural
Individual
CHRONIC ILLNESS

Fig 2 Agencies/Institutions

Hospital
Transplant Center
Renal Clinic
Dialysis Unit
Home Health
Dr.'s Offices
Nursing Home
Skilled nursing facility

Health care team members

Nurses: clinical nurse specialists
head nurses
staff nurses
transplant coordinators
office/clinic nurses; others
in a variety of settings.
Physicians: nephrologists; surgeons;
internists; dentists; others
Administrators
Technicians: xray; dialysis; others
Social Workers: hospital, dialysis unit,
transplant center
Dietitians: hospital, dialysis unit,
transplant center
Clerks; secretaries; billing personnel: in
all agencies.

Bibliography

American Nurses Association. (1988). *Nursing case management*. Kansas City: Author.

American Nurses Association. (1988). *Nursing practice in the 21st century*. Kansas City: Author.

American Nurses Association. (1980). *Nursing: a social policy statement*. Kansas City: Author.

Berwick, D.M. (1989). Continuous improvement as an ideal in health care. *New England Jouranl of Medicine*, 320 (1), 53-56.

Caplan, A.L. (1981). Kidneys, ethics and politics: policy lessons of the ESRD experience. *Journal of Health, Politics, Policy and Law*, 6(3), 488-503.

Editorial. (1987). Hospital challenges continue. *Medicine & Health Perspectives*, 2/2/87.

Editorial. (1987). Cost containment: the beat goes on. *Medicine & Health Perspectives*, 3/9/87.

Eggers, P.W., Connerton, R., McMullan, M. (1984). The medicare experience with end stage renal disease: trends in incidence, prevalence and survival. *Health Care Finance Review*, 5(3), 69-88.

Ellwood, P.M. (1988). Shattuck lecture - outcomes management. *New England Journal of Medicine*, 318 (23), 1549-1556.

Estes, C.L. (1986, June). *Social policy and aging: a research perspective*. University of California School of Nursing Sixth Helen Nahn Research Lecture, San Francisco, CA.

Fortner, R.W., Sparer, G., Luckenbill, L. (1988). *Capitation: A solution to the political chaos in ESRD reimbursement*. An unpublished paper.

Gornick, M., Greenberg, J.N., Eggers, P.W., Dolson, A. (1985). Twenty years of medicare and medicaid: covered populations, use of benefits, and program expenditures. *Health Care Finance Review*, annual supplement, 13-59.

Harrington, C. (1988). *Ensuring quality of nursing care: the why and how of outcome measures*. Manuscript for conference: "Quality Nursing Care of the Older Patient"; sponsored by University of California at San Francisco.

Kosterlitz, J. (1988). The coming crisis. *National Journal*, 8/6/88, 2029-2032.

LeBar, C. & McKibbin, R.C. (1980). *New organizational models and financial arrangements for nursing services*. Kansas City: American Nurses Association.

Lysaght, M.J. (1985). Contemporary ESRD therapy: quagmire or eschaton. Contr. Nephrology, 44, 275-284.

Manton, K.G. (1985). Future patterns of chronic disease incidence, disability, and mortality among the elderly. New York State Journal of Medicine, November, 623-633.

Rettig, R.A. (1980). Implementing the End Stage Renal Disease Program of Medicare. Santa Monica: The Rand Corporation.

Rettig, R.A. & Marks, E. (1983). The federal government and social planning for end stage renal disease: past, present and future. Santa Monica: The Rand Corp.

Strauss, A. & Corbin, J. (1988). Shaping a new health care system. San Francisco: Jossey-Bass, Inc.

Tonsfeldt, L. (1986). Cost management through case management. Personnel Journal, March, 74-79.

Wanzer, S.H., et al. (1989). The physician's responsibility toward hopelessly ill patients. New England Journal of Medicine, 320 (13), 844-849.

ARTHRITIS
FOUNDATION®

NATIONAL OFFICE

1314 SPRING STREET, N.W.
ATLANTA, GEORGIA 30309
TELEPHONE 404/872-7100

October 17, 1989

The Honorable John D. Rockefeller IV
Chairman
The Pepper Commission
140 Cannon House Office Building
Washington, D.C. 20515

Dear Senator Rockefeller:

I have enclosed a copy of our "Access to Long-Term Care for Individuals with Arthritis" document for use by your commission as you deliberate the issues of long-term care and health care for the uninsured.

Access to long-term care and health care services are two priorities of the Arthritis Foundation as evidenced by this document and our "Access to Total Care for People with Arthritis" document which was already sent to the Commission for their review. We look forward to the Commission's recommendations and solutions for comprehensive health and long-term care in the final report.

Sincerely,

Herb Sandvik

Herb Sandvik, Chairman
Government Affairs Committee

ACCESS TO LONG-TERM CARE FOR INDIVIDUALS WITH ARTHRITIS

A. Definitions

Impaired or Disabled: Functionally impaired people with arthritis who have a physical limitation that results in the need for some form of assistance in their daily lives. The amount and type of assistance needed will depend upon the nature and extent of the functional impairment.

Functional Impairment: For individuals with arthritis, functional impairments are primarily physical (not cognitive) and can be estimated by performance scores on the Activities of Daily Living (ADL) impairment scale as designed by Katz. The five basic ADLs are eating, using the toilet, dressing, bathing, and transferring from the bed or a chair.

Long-Term Care: The delivery of extended personal, social, and health care services in the home and community to disabled individuals with arthritis to assist them in their daily activities and to enable them to maintain independent lives in their communities.

In-Home Services: 1) Personal Services - these services include daily assistance in the home with meal preparation, shopping, housework, bathing, dressing, getting around, administrating medication and grooming. 2) Health Services - these services in the home include nursing care, homemaker and home health aide care, nutritional and dietary services, podiatry services, pharmaceutical services, therapeutic equipment and supplies, and occupational and physical therapy.

Community Services: These services primarily consist of social services provided by the community (some health care services are also provided) and include special transportation, senior centers which provide recreational activities and meals, adult day care centers, nutrition sites, and alternative housing arrangements. A few social service programs (may be funded by Older Americans Act or Social Services Block Grants) like Meals on Wheels, chore services, volunteer visitors, and telephone reassurance are provided in the home.

Skilled Care: Care provided by a skilled nurse in a licensed nursing facility or at home (must be provided by a home health agency that specializes in skilled nursing services) and available 24 hours a day for such observations as heart and lung evaluations, and blood sugar checks.

Nonskilled Care: Care provided by people usually without professional skills or training on an informal basis for daily living assistance. Care can be in a nursing facility or at home (some insurance policies may require the facility to be licensed).

B. Statement of the Problem

Today, 37 million Americans have arthritis. Arthritis is a chronic condition that can cause functional impairment. Many individuals with arthritis struggle with functional impairments that restrict their ability to maintain independent living. It is estimated that 70% of impaired elderly people have ongoing problems with arthritis. While approximately 21% of the disabled elderly reside in a nursing home, almost 80% live on their own or with family and friends in the community. The majority of care in the latter situation is unpaid, nonskilled, and provided at home primarily by women. Those living alone without informal caregivers are more likely to be institutionalized as a result of inadequate or expensive outside assistance.

In addition, disabled children and adults under the age of 65 account for 51% of long-term care patients. It is apparent that the issues of long-term health care involve all generations. The disabled elderly and nonelderly with arthritis have similar long-term care needs. Both groups are more likely to require nonskilled assistance in daily activities such as meal preparation, housework, getting around and personal hygiene. They are also likely to require functional rehabilitation such as physical therapies to reduce pain and increase mobility and occupational therapies specifically associated with the deformities of arthritis. Therefore, long-term care coverage for individuals with disabilities such as arthritis should consist of a coordinated team approach utilizing a variety of extended personal, social and health care services in the home and community with an emphasis on preventive services and noninstitutional care.

C. Long-Term Barriers

Barriers to quality long-term care services for individuals with arthritis who are impaired or disabled include the following:

1. Government programs have in the past placed an emphasis on inpatient and acute care services rather than outpatient and chronic (home or community) care services. In addition, the emphasis of long-term care services has been focused on the poor. Medicare now pays 100 percent of eligible expenses for 20 days and $67.50 for the next 80 days in an approved skilled-nursing care facility, if the stay follows a period of hospitalization and if the care is "medically necessary". The Medicaid program pays for skilled, intermediate, and custodial care in a nursing home but only when a person's assets and income drop below state Medicaid limits. This forces many elderly to "spend down" their assets to qualify for Medicaid. As a result, the Medicaid program has become consumed by costs for lengthy nursing home stays with little leftover for other care.

With regard to extended outpatient and community or home-based services, Medicare is primarily restricted to post-hospital acute care needs. Medicare will pay for home health visits only if all of the following four conditions are met: 1) the care a beneficiary needs includes part-time skilled nursing care, physical therapy, or speech therapy, 2) the beneficiary is confined to the home, 3) a doctor determines a beneficiary needs home health care and sets up a plan, and 4) the home health agency providing services is participating in Medicare. Medicaid pays only for some part-time nursing and home health aids if requested by a physician for those eligible. When these benefits are exhausted, individuals with disabilities are usually still in need of in-home services and have to use their own resources for this care. In summary, Medicare provides no coverage for nonskilled in-home care and Medicaid coverage is limited to personal care for the poor in a few states.

2. Medicare supplement insurance policies usually only cover post-hospital skilled care in a nursing home for a limited period of time. These policies pay some or all of Medicare's deductibles and co-payments. Some policies will cover services not available under Medicare, though most pay nothing for services that Medicare finds unnecessary. Custodial or intermediate nursing home care and in-home services are not covered.

3. Private insurance policies available for long-term care are very expensive and include many restrictions such as requiring prior hospitalization and limiting coverage for preexisting conditions. These restrictions frequently make it impossible for an individual with arthritis to qualify for any long-term care benefits in private policies. The benefits that are offered are mostly for nursing home care and not for home or community care. If home care is covered, most policies again require previous nursing home or hospital confinement. In addition, annual premiums vary significantly by age of the insured. A sixty-five year old may have to pay as much as $100 a month for premiums and for a seventy-five year old as much as $260 a month.

4. Employer-based health insurance does not cover long-term custodial care or home care for the chronically disabled. Most employers who already face huge liabilities for current employee's health insurance do not provide any type of long-term care coverage. The few employers who do offer this insurance usually require the employee to pay the entire premium.

D. Strategies for Increasing Access to Quality Long-Term Care Services

1. Become familiar with the reimbursement efforts of other chronic disease programs such as diabetes, hemophilia, and chronic renal failure. It may be possible to adapt similar successful approaches.

2. Collect and analyze information on the benefits of a coordinated team approach to the management of arthritis and of the individual team services (physical therapy, occupational therapy, patient education, etc.) within communities.

3. Work directly with third party payers on an individual basis to emphasize the importance of the team approach, the cyclical long-term nature of arthritis, the need for patient education, and the need for extended third party coverage of outpatient services, including reimbursement for periodic outpatient visits for individuals whose health status is not changing.

4. Urge Congress to amend Medicare so that skilled care is no longer a requirement for a beneficiary to receive home health services. In addition, expand the definition of home care to include other health services such as occupational therapy, podiatry services, therapeutic supplies and equipment, and nutritional and dietary services. If this requirement was removed, providers would not have to justify expensive skilled care when nonskilled care for assistance with daily living activities is all that is needed. This would save money since Medicare pays $75.00 and up for each skilled care visit. While there would be an increase in nonskilled care visits, the reduction in skilled care visits would compensate for the increase.

5. Federal and state initiatives should be adopted to set standards for private long-term insurance policies. These standards should consist of the following minimum standards:

* disclosure - policy must be at least guaranteed renewable.

* free look - after delivery, policy must provide a 30 day return policy for individual and group policyholders.

* prior institutionalization - no policy should require prior institutionalization or hospitalization as a condition for benefits.

* pre-existing conditions clause - this clause should not exceed six months for which medical treatment was recommended or received prior to the effective date of coverage.

6. Design a benefits package unique for the individual with arthritis so that their special requirements for long-term care are met. This might be done by a coalition with ACR, AARP, O.T., P.T., and nursing groups. This benefits package would have several option levels ranging from a minimum level to meet the barest essentials for adequate care, a more elaborate level, and a luxury or highest level of coverage.

7. State High-Risk Insurance Pools (there are currently 18 states with these pools) should be encouraged to provide eligible residents with coverage for long-term care. Risk pools should include effective case-management mechanisms that match individuals with arthritis with the appropriate long-term care services. In addition, join with other organizations to look into amending the ERISA of 1982 to no longer exempt self-insured health insurance

programs from contributions to state risk pools.

8. Tax Incentives:

a. Encourage states to offer tax incentives to buyers and sellers of long-term care insurance (several states are considering this).

b. Encourage the federal government to modify the tax code to allow for tax credits and/or deductions for personal care in the home.

c. Encourage the federal government to establish targeted medical individual retirement accounts to allow individuals to make contributions over an extended period of time to pay for long-term care costs. Although these accounts would not be sufficient by themselves, they could be combined with SHMOs or the above tax incentives.

9. Social HMOs: The Health Care Administration has granted Medicare contracts to four social/health maintenance organization (SHMO) demonstrations around the country. Each site sets its own copayment levels and benefit ceilings. These demonstration projects are prepaid health plans that provide all services paid by Medicare as well as different levels of ambulatory and home care services to Medicare beneficiaries who voluntarily enroll in the organizations. Home care services include skilled or intermediate nursing care, homemaker or home health aides, medical transportation and respite care.

10. Explore the use of home equity conversion loans for providing homeowners with income supplements over an extended period of time for long-term care.

11. Explore housing arrangements as an alternative to nursing homes. These alternatives such as house sharing, board and care homes, congregate housing facilities and continuing care retirement communities can be a viable alternative for individuals with arthritis who require daily living assistance but not nursing home care.

HUNTINGTON'S DISEASE SOCIETY OF AMERICA
140 W. 22nd Street, New York, NY 10011 (212) 242-1968

December 28, 1989

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Mr. Edward Howard
The Pepper Commission
140 Cannon House Office Building
Washington, D.C. 20515

Dear Mr. Howard:

The Huntington's Disease Society of America (HDSA) welcomes this opportunity to offer its recommendations regarding long term care to The Pepper Commission.

Huntington's Disease (HD) is an inherited, degenerative brain disorder that results in the gradual loss of control over both mind and body during a ten to twenty year period. The disease is always fatal. It strikes people between the ages of 30 and 50 causing slow deterioration of physical capacity, ability to communicate and the processes of thought and reason, frequently resulting in the need for total personal care. Currently, there is no cure for HD, no state of remission and no effective treatment.

It is estimated that 25,000 people in the United States are affected by HD. Since it is a dominantly inherited disease, each child of such a parent has a fifty percent chance of developing the disease. Thus, there are approximately 125,000 people who are at risk of also succumbing to it.

For any but the very wealthiest families in America today, the news that a family member has been diagnosed with HD can have catastrophic economic as well as physical and psychological consequences over time. The person affected by HD will lose income from employment, exhaust private medical insurance and will not be able to meet the costs of custodial care at home or in a nursing home through Medicare. As a result, many families are stripped of financial resources not only for the needs of a current afflicted family member, but also for dependent children and for the future needs of family members who are at risk of developing the disease. For such individuals and families the need for comprehensive, affordable long term care is an immediate priority.

Dedicated to the detection and care of those who suffer from Huntington's Disease and to its eradication through research.
Tax Exempt • Not-For-Profit • Member of National Health Council • National Coalition for Research in Neurological and Communicative Disorders (NCR) • National Organization for Rare Disorders • Independent Sector • A Voluntary National Health Agency founded as the Committee to Combat Huntington's Disease in 1967

Since its inception in 1967 by Marjorie Guthrie, widow of folk singer Woody Guthrie, who died of Huntington's Disease, the mission of the Huntington's Disease Society of America has been to: fund research into the causes, treatment and cure of HD, to locate and provide care for all those affected by HD, and to educate health professionals and the general public about HD.

HDSA strongly believes that long term care should be the right of every citizen and not the privilege of a few. Along with groups such as The Alzheimer's Disease and Related Disorders Association, Inc. and The National Association for Home Care, we urge the adoption of a federal, universal, comprehensive long term social insurance program that includes the following principles:

- o Eligibility for long term care services in all settings should be extended to all individuals who need them regardless of age, income or marital status. It must be based on an entitlement program according to need and not be a means-tested welfare program;
- o Eligibility requirements should be based on functional, cognitive or behavioral disability and limitations and not on age, and must cover the need for supervision of activities of daily living (custodial care);
- o Both public and private long term care insurance programs must cover the full range of services and care needed by people with HD, and for as long as they need them;
- o Benefits should allow maximum flexibility in meeting individual needs -- ranging from home care, respite care, day care and nursing home care as a last resort;
- o Families should be a primary partner in coordination of care and their preferences should be respected. Respite and other social and financial support services should be available to caregivers to permit those for whom they provide care to remain in the community for as long as possible;
- o Adequate education and training for long term care providers should be an essential component of care.

- The long term care program should be based on traditional social insurance principles and spread the financial risk as broadly as possible. The individual or family should not be impoverished in order to receive care;
- Coverage and financing should be uniform throughout the nation and should not stigmatize those in need;
- The program should be supported through sources of financing that are as progressive as possible; and, finally
- Cost containment provisions should be built into the program.

Again, the Huntington's Disease Society of America appreciates this opportunity for presenting its recommendations which we hope will be of assistance to the Commission in formulating its report to the United States Congress in March.

Sincerely,

Stephen Bajardi
Stephen E. Bajardi
Executive Director

Rita Faden
Rita Faden
President

Douglas Marr
Douglas Marr
Chairman of the Board

Merrill Lynch,
Pierce, Fenner & Smith Inc.

Administrative Offices
800 Scudders Mill Road
Plainsboro, New Jersey 08536
609 282 1622

Mailing address:
P.O. Box 9000
Princeton, New Jersey 08543-9000

John L. Steffens
President - Merrill Lynch
Consumer Markets

Merrill Lynch

October 12, 1989

Mr. Edward F. Howard
General Counsel
United States Bipartisan Commission
on Comprehensive Care
140 Cannon House Office Building
Washington, DC 20515

Dear Mr. Howard:

Attached is my testimony which presents Merrill Lynch's perspective on long-term financing approaches, for inclusion in the record of the Pepper Commission's October 5, 1989 hearing.

While I would have been pleased to appear before the Commission to present the testimony and answer questions, I understand the Commission's need to limit the number of live witnesses. Merrill Lynch greatly appreciates the opportunity to participate in the Commission's deliberations through written testimony, and I personally thank you for your willingness to include our views in the official record of the hearing.

I understand from Peggy Ingraham, who has spoken with you on my behalf, that a synopsis of the Merrill Lynch testimony will be helpful to Commission members in their future deliberations. A one-page abstract is included with the testimony.

Again, let me commend the Commission for its important work and for its decision to include a wide spectrum of representatives from the public and private sectors in its hearing process. Should you or any Commission members wish to discuss Merrill Lynch's view in detail, we would be delighted to meet with you.

Sincerely,

SUMMARY OF WRITTEN STATEMENT OF
JOHN L.STEFFENS
PRESIDENT & CHIEF EXECUTIVE OFFICER, MERRILL LYNCH CONSUMER MARKETS
TO THE U.S. BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE

October 5, 1989

The future financial liability of long-term care is immense. For individuals to adequately prepare for long-term care, a combination of financing mechanisms will be required. The answer is not a singular public or private insurance program but a joint effort among individuals, the public and private sectors. The total solution must be cooperative and multi-tiered, emphasizing individual responsibility, private sector creativity, and public sector incentives and safety nets.

Individuals by themselves generally cannot save or accumulate sufficient assets to protect against the long-term care liability. For any long-term care financing product to be both affordable and accessible to a majority of individuals, the vehicle must combine the elements of insurance and long-term saving. Personal saving can go a long way toward defraying the cost of insurance. Pre-funding for the liability over time and compounded growth can build the resources to pay for a substantial portion of long-term care.

Merrill Lynch has developed a long-term care financing model, the Health Care Management Account (HCMA), that couples the pooled risk of insurance with long-term saving. The HCMA would be a portable dual-process account combining: (1) a saving vehicle and (2) a group insurance policy. The account would allow for pre-tax defined contributions for the duration of a person's working life to retirement. The HCMA would be constructed so that a portion of each contribution would be diverted into an insurance pool and credited toward a long-term care insurance premium. The remainder of the contribution would be deposited in a savings account. Internal buildup of the saving account would be tax deferred. After retirement, HCMA saving spent on long-term health care products and services would be tax free.

The HCMA utilizes saving and insurance in a very efficient manner. The individuals would be required to incur a predetermined level of expenditure from the saving portion of the account before insurance coverage would start. This order of utilization allows the insurance coverage to provide for the catastrophic financial risk but at dramatically cheaper insurance rates. Further, the HCMA design assures coverage which might otherwise be unaffordable if purchased late in life.

The HCMA stresses the individual's role in providing for the future liability posed by long-term care. In exchange, the HCMA requires tax incentives to encourage participation. The Federal government can effectively use tax incentives to encourage savings and/or the purchase of long-term care insurance. We urge the Commission to consider our HCMA as an innovative, equitable, and effective savings/insurance long-term care financing vehicle which will enable affordable and accessible long-term care coverage to be within reach of a substantial portion of the population.

WRITTEN STATEMENT OF
JOHN L. STEFFENS
PRESIDENT & CHIEF EXECUTIVE OFFICER,
MERRILL LYNCH CONSUMER MARKETS
TO THE U.S. BIPARTISAN COMMISSION
ON COMPREHENSIVE HEALTH CARE

October 5, 1989

Over two years ago Merrill Lynch organized a firmwide task force with the broad mandate of addressing the financial and economic implications of our aging society. Our task force isolated long-term care as one of the most onerous of financial liabilities facing the elderly. In response to this, Merrill Lynch has become deeply involved in attempting to create innovative solutions to the long-term care financing problem.

Because long-term care is extremely costly, both to society and individuals, the financing issue has emerged as a major political debate. Merrill Lynch recognizes the importance of the Pepper Commission's task and commends the Commission for encouraging widespread public participation in its deliberations on long-term care financing. We must all work together to develop solutions that enable broad participation, are truly comprehensive, flexible, and involve both the public and private sectors in the financing process. The magnitude of long-term care costs necessitates a shared responsibility among all sectors of society.

The Private Sector and the Individual

Whereas most of the private sector has focused its attention on long-term care insurance, Merrill Lynch believes long-term care financing must be viewed in a much broader context.

Insurance is certainly an essential component of any long-term care financing vehicle, specifically because long-term care is an insurable risk. However, the private sector market for long-term care financing products is not solely constrained to insurance and must not be solely defined as such. By expanding the scope of financing options we can have greater flexibility in designing solutions.

Merrill Lynch is absolutely convinced that for any long-term care financing product to be affordable and accessible to a majority of individuals, the vehicle must combine the elements of insurance and long-term saving. By exploiting the powers of time and compounding in conjunction with the pooled risk dynamics of insurance, the catastrophic costs of long-term care can be adequately reduced. The important issues are division of responsibility and order of payment.

How much saving responsibility should the individual be required to bear?

We believe that a system should be designed so that those individuals capable of providing some measure of protection for themselves are encouraged to do so. By assuming a level of personal responsibility for long-term care saving, individuals greatly reduce the cost of insuring additional protection above and beyond their personal means. This is the general concept of insurance deductibles. Assuming a small portion of this cost responsibility goes a long way toward affordable long-term care coverage.

To pay a reasonable deductible the individual must be able to accumulate savings. Thus, an appropriate long-term care funding vehicle should allow for some level of pre-funding of the first dollar costs. In addition, a funding vehicle should have a positive effect on savings and hence the economy.

A Long-Term Care Financing Model

We urge the Commission to consider the development of a long-term care vehicle which couples the pooled risk of insurance with long-term savings. We have developed such a model, the Health Care Management Account (HCMA), which will be described below.

Operationally the HCMA would be a portable dual-process account in the individual's name. The HCMA combines: (1) an asset accumulation saving vehicle and (2) a group insurance policy. Contributions to the account would be shared by the individual and the employer. The account would allow for pre-tax defined contributions (contribution level would be defined by program entry age and ideally fixed until retirement) for the duration of a person's working life to retirement. The account would be constructed so that a portion of each contribution would be diverted into an insurance pool and credited toward a long-term care insurance premium. The remainder of the contribution would be deposited in a savings account. Internal buildup of the saving account would be tax deferred. While both parts of the account are required, the individual only has discretionary use over the saving portion.

After retirement, the saving portion of the HCMA that is spent on long-term health care products and services would be tax free. The individual would be required to incur a predetermined level of expenditure for long-term care costs from the saving portion of the account before the insurance portion of the account would start. The level of saving expenditure can be viewed as analogous to an insurance deductible. The account could be designed to accommodate any pre-set level of saving depletion (i.e., 20%, 40%, 80%) and the level of insurance protection would be priced accordingly.

Since the HCMA saving account can accumulate over time without constraint, it is feasible that growth could be considerably more than would be required to fund the original deductible. Thus, cash withdrawals for non-health-care expenditures would also be permitted, but taxed at prevailing rates. These withdrawals would be allowed according to a pre-determined actuarial formula. Any remaining saving would belong to the individual's estate after death.

The HCMA would be a construct within which the funds for both the long-term care insurance and its deductible could be accumulated. The HCMA was designed to: (1) protect other retirement and saving assets from being drawn upon to pay for the deductible or total long-term care expenses, (2) force saving dollars to be spent prior to receipt of insurance benefits, thereby greatly reducing the cost of insurance, (3) avoid concerns of insurability as age increases since insurance would be underwritten upon account opening and in a sense "coinsured" by the saving account, and (4) allow the individual great flexibility and control in choosing long-term care services; the individual has complete discretion over saving account expenditures for long-term care after satisfying the deductible.

Basically, the HCMA resembles what might be viewed as a "cash accumulation health policy." This concept is common in the realm of life insurance, but is not, as yet, typical for health-related policies.

As noted earlier, the order in which funds are used is critical to creating affordable coverage. For example, examining a typical indemnity long-term care policy, if the deductible were increased from the common 20 day exclusion to 100 days, the premiums would be reduced by approximately 15% for a 65 year old. With even larger deductible periods such as five months to one year, the insurance rates would be reduced by about 23%.

Since the HCMA contributions begin at an early age (below 50), insurance rates are reduced up to 60% from the age 65 rate. The dramatically cheaper HCMA insurance rates would provide long-term care coverage which would otherwise be typically unaffordable to the retired American.

The HCMA could also be financed through tax-free transfers from existing retirement savings pools (i.e., IRA, KEOGH, SEP, pensions, 401(k)). This would specifically serve older persons unable to capitalize on a long-term compounding effect.

HCMA Feasibility

Merrill Lynch has run model simulations of the HCMA to test its viability in terms of coverage, affordability, and macro-economic implications.

The simulation results indicate that under a voluntary HCMA proposal about half of persons who are under age 45 in 1989 would have adequate long-term care insurance by the time they reached ages 65-69; under a mandatory HCMA proposal, over 70 percent of persons who are under age 45 in 1989 would have long-term care insurance by the time they reached ages 65-69. Almost all of these individuals would be able to cover most or all of their long-term care costs with their HCMA saving and insurance.

In addition to its impact at the individual level, HCMAs could significantly affect the economy. A large share of HCMA saving would represent new saving. There would be a resulting increase in both the capital stock and personal income which could help provide the real resources that would be required to pay the costs of long-term care and other needs of an aging population in the 21st century.

Changes in the federal tax code would be required for implementation of an HCMA. Because HCMA contributions and interest earnings would not be taxable, Federal tax revenue would be reduced. However, this loss would be partially offset by future reductions in Federal and state spending for Medicaid and other public long-term care programs. Further, the dynamic economic effects of increased saving resulting from the HCMA would offset static revenue implications in the near term.

Tax incentives must be developed to assist individuals and employers in recognizing the necessity of pre-funding the future liability posed by long-term care. Currently there is an inherent bias in the tax code which penalizes saving (by taxing both the income dollars funding the saving and the earnings created by saving) and rewards consumption (by not taxing expenditures). This must be corrected to create the necessary pool of savings for the future.

By shifting an equitable portion of the long-term care responsibility to individuals, the HCMA will also help bolster the viability of our current social support systems. The demographic shift of the baby boomers from work to retirement will only further strain the system's ability to meet current financial obligations. We need to strengthen these systems by alleviating future liabilities, not increasing them.

The Commission has indicated it is analyzing options for long-term care which include: (1) preferred tax treatment of long-term care insurance for individuals and employers and (2) encouraging savings for long-term care insurance through tax preferences. Merrill Lynch strongly endorses these two options as constructive and practical.

Summary

The answer to long-term care financing is not insurance alone and it is not saving alone. The solution requires both insurance and saving, as well as planning so that time and compounding can create the funds which make long-term care affordable. We hope the Pepper Commission strongly considers our HCMA model as a broad and equitable solution for a substantial piece of the long-term care liability. With such a vehicle, the government will be in a better position to maintain a base level of support for those incapable of saving or for those who have exhausted their resources.

The development of a long-term care financing solution only partially addresses the problems associated with long-term care. Education about long-term care, its needs and costs are paramount. Merrill Lynch's initiatives in these areas have included both internal and external communication. Merrill Lynch has made a commitment to educating its clients, employees and the public on long-term care issues through a range of communications, surveys, and public speeches.

Merrill Lynch commissioned a number of research reports from individuals, consulting groups and academics to investigate the financing implications of long-term care. Several of these reports were presented at a Merrill Lynch hosted symposium in Washington, D.C. last December entitled "Financing Long-Term Care: A Tripartite Approach." The seminar addressed the economic and financial issues arising from a demographic shift toward an increasingly elderly population.

Much of what will happen with long-term care in the future will be modeled after the recommendations the Commission puts forth. Thus, the Pepper Commission's recommendations will have important implications for future generations. A cooperative effort involving individuals, the public sector and the private sector is needed to forge a financially strong and secure future. Merrill Lynch stands ready and willing to provide any support it can to help the Commission reach its goals.

STATEMENT OF
JOSEPH W. WESTBROOK, PRESIDENT
NEA-RETIRED
ON
CATASTROPHIC AND LONGTERM HEALTH CARE
BEFORE THE
BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE
WASHINGTON, D.C.
OCTOBER 5, 1989

Mr. Chairman and Members of the Commission:

As president of NEA-Retired, a 100,000-member affiliate of the National Education Association, I appreciate this opportunity to comment on our concerns in the area of health care access and proposals to resolve the most critical problems.

A major concern of every American family is access to affordable, quality health care. To more than 37 million Americans, most of whom work full time, health insurance is either unavailable or beyond financial reach.

An estimated additional 12 million Americans are so underinsured that virtually any necessary medical care is beyond the scope of the family budget.

There are serious imbalances in the location of medical facilities and medical practitioners, and this imbalance has a serious impact on the availability of care.

Health care costs have escalated at many times the rate of the Consumer Price Index generally, to the point where the United States spends more of its Gross National Product on health care than any other industrialized nation.

We also have the dubious distinction of being the only industrialized country -- other than South Africa -- without a national health care policy and system in place.

We cite these facts by way of warning and as a mere sampling of evidence that the American health care system, despite impressive advances in technology and sophistication of practice, is essentially a non-system -- an aggregate of services, practices, and private and public policies that lack the cohesion necessary to ensure that every American enjoys the basic right to decent, humane, affordable, quality care, regardless of income or social status. Because these problems confront not only NEA members but their students, their families, and everyone else in our society, NEA and NEA-Retired believe that the situation will continue to deteriorate until the Congress responds with the development of a unified, sensible program of national health insurance. Such a program would include the Medicare and Medicaid programs and all existing health activities of the federal government, but would go beyond that and establish a nationwide, state-administered program similar but not identical to the Canadian model. We refer the Commission's attention to the attached summary of the Health Partnership plan recently published by the Committee for National Health Insurance, of which NEA is an active supporting member organization.

Until the development and implementation of a rational universal system to guarantee access to health care, there are urgent matters requiring the immediate attention of the Congress. We urge three immediate priorities in this area:

1. Correction of the financing method employed in the Catastrophic illness program;

2. Enactment of S. 768, a bill to require all employers to provide basic health benefits to employees and their dependents (a summary of which is attached); and

3. Enactment of a sound program to provide longterm health care for the chronically ill in both the institutional and home settings.

We urge the Commission to consider each of these measures and to recommend them to the 101st Congress.

Catastrophic Illness Insurance

Catastrophic Illness Insurance came about as a response by Congress to the economic ravages of chronic illness and other diseases for which the course of treatment is inordinately expensive. Public Law 100-360 was a step in the right direction as far as coverage is concerned, particularly with respect to removing or relaxing limitations on institutional care and in the provision of both preventive screening and prescription drug reimbursement. We are aware that the federal budget deficit prevented Congress from making an all-out assault on these high-ticket health care problems, but the outcome of last year's legislation is viewed by a substantial number of NEA members as far short of satisfactory.

In particular, our members believe that the establishment of the Catastrophic Illness program outside the social insurance principles that have traditionally governed Social

Security and Medicare was harshly discriminatory against the beneficiaries (since they bear the entire burden of financing) and a bad precedent in the area of health care specifically and in public policy in general. In their view, which has been stated vociferously to us in countless letters and other personal communications, the benefits are far outweighed by the financial burdens that the legislation imposes. They recoil at the idea of a huge increase in the basic Part B premium, accompanied by an income tax surcharge. They are particularly incensed by the idea of a user fee that tries to disguise itself as insurance.

We think these members are absolutely correct in their perception of this program. But we do not side with those who would repeal it, nor do we feel the program should be amended simply by reducing the premiums and/or surcharge simply to bring revenues and benefits into closer balance.

The fact is that the Medicare system is still in danger of the same kind of shortfall that was experienced in the OASDI program seven years ago. The Congressional response in that case was not to curtail available benefits, but to make new financing arrangements that were generally fair -- but more importantly, were in keeping with the principle of social insurance: the sharing by the entire community of a commonly held risk.

Applying these principles to the Catastrophic Illness program, we urge the Commission to recommend a legislative package proposed by Rep. Edward Roybal (D-CA), chairman of the House Select Committee on the Aging. Mr. Roybal's proposed "Catastrophic Fairness Amendment" would accomplish two principal objectives:

1. *It changes the financing of the Catastrophic program by cutting the supplemental premium/income surtax rate in half; retains the current basic Part B premium; and retains the current deductible amount for prescription drug benefits.*

2. *It provides Medicare coverage of longterm home care for the chronically ill elderly, disabled, and children. It would also put approximately $1 billion a year into improving Medicaid coverage of nursing home care costs.*

The mechanism for accomplishing these objectives is removal of the cap on the Hospital Insurance portion of the FICA tax. It thus uses a financing method proposed last year by Rep. Pepper -- a method for which the there seemed to be substantial support but which foundered on the unanticipated objections of certain House leaders. We believe this financing proposal to be eminently fair, since it affects only the top five percent of wage earners. It could be modified to accommodate the legitimate concerns of small business employers, along the lines proposed in S. 768 by Senator Kennedy.

Basic Health Benefits

We now know that more than two-thirds of the 37 million uninsured and the estimated additional 12 million underinsured persons in America are employed full time. It is shocking to us that one-fifth of the entire population has such limited access to affordable health care. Public hospitals are literally being driven out of existence in many parts of the nation by the burden of uncompensated care. To be sure, the cost is being picked up in many instances by those who are covered; their health insurance premiums (or those being paid for them under contracts or informal arrangements with employers) are increased as the burden of caring for the medically indigent is shifted over to the insured workers.

To address these problems, Sen. Edward M. Kennedy and Rep. Henry Waxman have proposed the Basic Health Benefits for All Americans Act, (S. 768, H.R. 1845) which requires employers to provide all workers and their dependents an efficient and cost-effective package of health insurance that covers doctor fees, hospital services, preventive and diagnostic services, and a catastrophic coverage limit. This measure would extend health protection to all workers and their families with minimal cost to the government. It would protect small businesses by establishing regional contracting programs and a subsidy for those businesses whose cost of providing basic benefits would exceed five percent of gross revenue.

The Kennedy-Waxman proposal would close a major gap in health care, and should receive careful consideration by the Commission.

Long Term Care

Even with provision of health care for uninsured workers, there is another large group of individuals and families severely disadvantaged by current programs for the chronically ill. One of Claude Pepper's unfulfilled dreams was enactment of a longterm care program. Despite growing awareness of the need for federal legislation to keep individuals and families from being crushed by the costs of home health care and skilled nursing home services, the 100th Congress failed to act on the problem. We consider it tragic that agreements between Mr. Pepper and the House leadership broke down under a procedural vote which was, in reality, simply the outcome of a jurisdictional dispute. As a result, precious time was lost in fashioning a program that would follow the social insurance principles of Social Security and Medicare, cover for the first time the disabled and chronically ill children, and do so with minimal disruption of the federal budget. We urge the Commission to revisit the Pepper proposal and to recommend that it be adopted, with provision for phasing in a program that would improve and broaden the skilled nursing home coverage under Medicare.

Until the establishment of a cohesive, universal health care system, which is the only viable complete solution to access, cost, and quality problems, this set of legislative proposals offers the most sensible, practical, and politically acceptable approach to meet what are clearly the most urgent health care issues before the Commission and the Congress.

THE HEALTH CARE PARTNERSHIP PROGRAM

The Health Care Partnership program is a sweeping health care reform package drafted by the technical committee of the Committee for National Health Insurance. Its principal features are:

(1) Universal coverage
(2) Quality Control
(3) Cost control

The Health Care Partnership program is a sweeping health care reform package drafted by the technical committee of the Committee for National Health Insurance. Its principal features are:

(1) Universal coverage
(2) Quality control
(3) Cost control
(4) Federal/state administration

Under this plan, the federal government would require that all Americans be covered under a universal health care plan, administered by the states under broad federal guidelines respecting coverage, benefits, financing, quality control, and cost control. The program would include, at the outset, such existing federal programs as Medicare and Medicaid.

Financing of this plan would be shared equitably by the federal and state governments, and decisions about how to finance the state portion would be left to the states themselves.

The program would guarantee everyone access to all necessary medical care, including physician services, hospitalization, mental health care, and long term health services for the chronically ill. Access to quality care would be the statutory right of all Americans without regard to age, race, sex, national origin, or previous health conditions.

Quality and cost controls would be developed by the states under the broad federal guidelines to assure a sufficient degree of uniformity that no person would be denied quality care when he or she needed it.

Cost controls would be accomplished by a system of prospective budgeting, under which health care providers would negotiate fees with the states each year -- and be bound to accept those fees as payment in full for services rendered. Elimination of current mountains of paperwork would contribute substantially to cost reduction; a person would simply present a health care card to a doctor or other health care provider and never see a bill.

Quality controls would be encouraged through strict enforcement of peer review and other mechanisms that would sharply reduce the incidence of malpractice suits, superfluous or redundant procedures, and other practices which currently increase the cost of health care far beyond the cost of living generally without resulting in high quality care.

The right of universal access would stop the steady erosion of the fiscal base for public hospitals, which currently bear the high cost of treating the uninsured and the medically indigent.

Although the initial cost of this program would be substantial, the savings of scale and more efficient administration of a unified system would quickly reverse the current trend to higher and higher medical costs.

BASIC HEALTH BENEFITS FOR ALL AMERICANS ACT - 101st Congress
as proposed by Sen. Edward M. Kennedy and Rep. Henry Waxman

PRIVATE PROGRAM

The bill incorporates the provisions of S. 1265, the Minimum Health Benefits for All Workers, as reported in the 100th Congress by the Senate Labor and Human Resources Committee. Under this legislation, employers provide all workers and dependents a package of health insurance including:

-physician services
-hospital services
-diagnostic tests
-prenatal/well baby care
-limited mental health coverage
-catastrophic coverage ($3,000 out-of-pocket limit)

The bill sets limits for deductibles and copayments. The maximum deductible for an individual would be $250 ($500 for a family). Copayments would not exceed 20 percent. There would be no deductible or copayment for prenatal and well-baby care. The minimum employer share of premiums would be 80 percent. There would be no exclusion from coverage based on the health status of a covered individual.

Small businesses would be protected from excessive costs by the establishment of regional contracting arrangements and a subsidy for small businesses if the cost of the minimum plan exceeded five percent of gross revenues. Employers would be allowed to make a proportional contribution for parttime employees working between 17.5 and 25 hours per week. Employees working less than 25 hours per week could decline coverage.

The private program would also establish full deductibility of premiums for the self-employed.

PUBLIC PROGRAM

All Americans would be assured health insurance coverage by the year 2000 under a public-funded program for any person not covered by an employment-based program. In response to budget constraints, the public program would cover the uninsured in three steps:

-Upon enactment, all uninsured persons with incomes below the poverty level (7.1 million people);
-In 1996, all uninsured persons with incomes between 100 and 185 percent of the poverty level (4.9 million people); and
-In 1999, the remaining uninsured population (8.8 million people).

The public program would offer the same benefits as the private plan. There would be no copayments, deductibles, or premiums for those with incomes below the poverty level. The public program would be administered by the states under federal guidelines, with appropriate federal matching funds for the states.

Source: Office of Sen. Edward M. Kennedy (D-MA).

The following is a statement of Richard H. Smith, President of the American Health Care Advisory Association for the United States Bipartisan Commission on Comprehensive Health Care. Respectively submitted December 6, 1989.

Chairman Rockefeller, Co-Chairman Durenberger and Members of the Commission:

On behalf of the Membership and the Board of Directors of the American Health Care Advisory Association (AHCAA), we wish to express our thanks to you and the fine professional staff of the Commission for the opportunity to submit a formal statement of our position on the problem of long-term care for consideration by the Commission.

We appreciate the enormity of the task of the Commission in analyzing the health care delivery and financing systems in the United States and making recommendations to Congress for improvement, particularly in the financing and delivery of long-term care. These issues are of great interest to the Association.

Founded in 1982, the American Health Care Advisory Association (AHCAA) is a private organization representing 400,000 individual members nationwide. The goal of the Association is to meet the health and lifestyle needs of the self-employed and small business owners. The Association is also a clearinghouse for health education, wellness and prevention programs.

We commend the Commission for its deliberations and efforts to come to grips with what is perhaps the most difficult and complex of the health care delivery problems facing the Congress and the Administration: The provision of long-term care for the nation's elderly.

Next year, Congress is expected to commence debate on the many issues subsumed under the category of long-term care. And that debate promises to be momentous for one fundamental reason: the subject Members will deal with, unlike so many others Members regularly address, directly affects every American family. Virtually no one is immune from the problems surrounding care for the elderly. Virtually no one will escape the strong emotional and financial sacrifices that are, and have been, necessary to care for the elderly.

The Commission has received an excellent body of testimony from various experts on the current dimensions of the problem of long-term care. We cannot improve or add anything in that regard to what the Commission has already received.

The basic facts are simple. The current demand for quality long-term care is great. The future demands for long-term care promise to be enormous. The current private and public arrangements are not yet equal to the enormity of the task that must be faced.

According to HHS, there are approximately one million elderly persons residing in nursing homes throughout the United States. HHS officials further estimate that there are approximately another 5 million elderly citizens who regularly receive help in the tasks of daily living from families, friends, relatives, even neighbors and various private, religious and community organization, who assist the elderly. The continued dedication of family and relatives is of value beyond calculation. Nor can we overestimate the tremendous value that many worthy private and religious institutions perform in this vital undertaking. For this reason whatever policy options Congress chooses in order to enhance or expand those private sector support systems will rebound to the best interests of America's elderly citizens.

Policy in this area calls for the utmost in political prudence. On the most basic and important level of care, we should not expect government programs to supplant fundamental family responsibilities. Surely, we would not wish to see taxpayers subsidizing the estate inheritance of middle and upper income children who would otherwise be shouldering the responsibility for the care of their disabled parents. But at the same time, government policy should be sensitive to the problems of families, trying to care for physically and mentally infirm elderly, whose deteriorating condition is often beyond the capacity of immediate family members to cope effectively. This is especially true in cases where the elderly are suffering from particularly debilitating conditions, such as the loss of mental and physical capacity either through Alzheimer's disease or other vascular-related dementias associated with aging. The care required in these instances is virtually full-time, requiring the love and dedication on the part of family members that is little short of heroic. With the passage of time, the only viable option for these families is often institutionalization of the elderly in a nursing home. This is a last resort usually, accompanied by guilt, emotional trauma and invariably either impoverishment of the elderly or financial hardship.

Institutionalization is often bitterly resisted by the elderly. It is they who suffer the greatest hardship, including the loss of familiar surroundings, the sale of homes and other assets and, in far too many cases, the reduction of once prosperous, hardworking persons to poverty status. Congress has rightly recognized this problem and its decision to retain the "spousal impoverishment provisions" of the recently repealed Medicare Catastrophic Coverage Act is a wise and prudent measure of assistance to the elderly. At the same time, AHCAA believes that the Commission should also accommodate the very real desire on the part of the elderly to remain in their homes as long as possible and enhance home health care options for the elderly, including assistance from nonprofit hospitals, home health aides as an alternative, wherever possible to institutionalization. Any public sector expansion in this area, however, should not preempt private sector efforts. While we have no specific recommendations to make in this area, we sincerely hope that the Congress will explore ways to multiply private sector opportunities for families to procure home health care assistance and enhance private sector options, such as residence homes or intermediate care facilities, short of full custodial care in skilled nursing facilities.

We believe that the timing for comprehensive legislative action in the area of long-term care is appropriate. We have enough lead time, but just enough to make the public and private adjustments necessary to absorb the full brunt of what Drs. Philip Brickner and Anthony Lechich et al. have called America's coming "tidal wave" of aging. (See Philip W. Brickner et al. Long Term Health Care: Providing a Spectrum of Services to the Aged. (New York: Basic Books, 1987)

The Commission has doubtless been presented with comprehensive statistics on the demographic revolution that is now taking place in the United States and the magnitude of the expected impact of this revolution on America's health care delivery system. Not only is the American population rapidly aging, it is enjoying greater longevity. As Brickner and Lechich, et al. have shown, the elderly population of the United States increased 100 percent between 1950 and 1980, or twice the rate of the general population. It is further expected that over the course of the next 30 years that rate of increase will be maintained or even increase. (Brickner et al., Long Term Health Care, p. 287)

The impact of this growth on our health care delivery systems is bound to be dramatic. As former Secretary of the Department of Health and Human Services, Dr. Otis Bowen told Congress in testimony on the issue of Catastrophic health care for the elderly, the gravity of the increasing health problems of the aging population will translate directly into major social problems, problems related to the devastating financial consequences for American families of catastrophic illness and long-term incapacitation. More recently, Dr. Marshal Folstein of the Johns Hopkins University predicted a huge increase in the frequency of Alzheimer's, in particular, noting that within the next 20 years, under current trends, the United States will need twice the number of beds in nursing homes. Right now, the fastest growing group in the American population is that group 85 years and older, the very old. And it is among the very old that the greatest demands will be made on America's health care delivery system. They are more likely to suffer chronic illness and mental and physical debility. As Brickner, Lechich et al. note, "The implications of this in numbers of extremely old people are noteworthy. It is these people who pack our nursing homes now; who occupy beds in our acute care hospitals because no effective plan for discharge exists; or who are sent home prematurely, only to fail at home or be readmitted, because assistance is not available." (Brickner et al. Long Term Health Care, p. 287.)

Beyond this current population, of course, is the great block of now graying baby boomers, who, in the next 25 years will start to fold the Medicare program and present, in sheer numbers, tremendous challenges to whatever long-term health care delivery system we manage to have in place.

These factors make it imperative for the Congress to initiate legislative activity in the 101st Congress. An effective long-term care policy will surely be expensive. No matter what option or set of options Congress should finally choose, they are bound to be costly. But there is an ever greater cost to be borne if action is not forthcoming on this critical area; it is the cost of doing nothing. The cost of doing nothing is prohibitive. Not only will precious time be lost in developing an appropriate infrastructure within the health care delivery system to manage the inevitable tide of health care services for a rapidly aging population, but also the costs to the public sector will mount and those costs, in the form of outlays and higher levels of taxation and inflation, will prove astronomical. The simplest extrapolation of current costs and trends is conclusive of the point. According to HHS, a total of $36 billion was spent on nursing home services (in 1985 dollar); $16 billion was paid out-of-pocket directly by elderly citizens; another $17 billion was paid through the Medicaid system. Given the rapid aging and longevity of the American population, without innovative means of providing private sector care, the financial burdens on the Medicaid system will be enormous. The social costs, in terms of the impoverishment of a large section of the elderly population, will also prove catastrophic.

AHCAA does not propose any comprehensive, self-contained public/private sector plan; nor does the Association endorse any specific legislation now before the Congress. But such a plan is certainly in order. Such a plan should incorporate both public and private efforts and address a variety of areas essential to a successful long-term care policy. These would include respite care, the employment of paraprofessional services to families who need assistance, adult day care, foster care, certified home care programs, long-term home health care and policies governing skilled nursing facilities. Again, while government efforts, both at the state and federal level, can undoubtedly play a vital role in a long-term care program, we believe it advisable that the overwhelming burden of providing access and financing of long-term care should remain with the private sector.

For government policy the first priority should be the improvement of current governmental functions of the federal and state level, ensuring better coordination and targeting of current programs, the elimination of overlap and duplication and the streamlining of services to the elderly who are eligible for them.

MEDICAID POLICY

Because long-term care costs already consume a disproportionate share of the Medicaid Budget, the Commission should recommend the restructuring of Medicaid to meet the increasing demands for long-term care among the elderly.

Medicaid is the central federal/state matching program that provides health care services to the indigent, including the elderly poor. Medicaid was originally designed to handle health problems of the poor and usually of an acute rather than long-term character. With expansion to accommodate pregnant women and children above the official poverty line, with greater pressures to provide health care to the poor, especially in the inner cities, and with the increasing burden that the AIDS virus is expected to impose on Medicaid resources, the capacity of the program is already severely strained. As an administrative and policy matter, Medicaid has literally become all things to all sorts of people.

The Commission should consider revamping the administrative structure of the Medicaid program; the current functions of the program should be streamlined and Medicaid funding and provision of services for long-term care should be carried out separate and apart from the rest of the Medicaid programs. Those services focus on acute care for the poor, women, children, patients with AIDS and elderly in need of acute care assistance.

By carving out long-term care assistance in to a separate program, the appropriate HHS staff would be able to concentrate on the very specific policy and administrative needs and care concerns of the elderly in need of long-term care in the Medicaid system would serve the interests of both the non-elderly poor and the elderly in need of Medicaid assistance.

TAX CODE CHANGES

While we recognize that there is a great reluctance on the part of Congress to reopen debate on the tax code, especially after the historic deliberations that went into the 1986 Tax Reform Act, we believe that is necessary to reconsider the tax code in order to make prudent adjustments to foster the growth of private sector long-term care alternatives. Congress has long employed the tax code, not only as a means of generating revenues for the federal government and its programs, but also as an instrument to promote widely desirable social and economic policies. It is hard to conceive of any more desirable social or economic policy than the private provision of long-term care for the elderly, enhancing the quality of their lives, protecting their homes and properties and sparing our public assistance programs the additional administrative and financial burdens.

Given the dimensions of the problem confronting us, the dual objective of our public policy measures should be stimulate a demand for long-term care insurance instruments on the part of the public and to encourage the supply of such plans on the part of the private insurance companies.

On a very limited basis this is already being done. Indeed the most significant development in this respect was the recent Internal Revenue Service ruling that gives insurance companies the same tax advantages as reserves for life and health insurance. The IRS ruling provides for a measure of predictability in insurance planning, encourages the formation of reserves and renders such long-term care policies that are much more affordable for the general public. But much more needs to be done.

Private insurance can serve two related functions in the care of the elderly: (a) the provision of health care and (b) the protection of their financial assets against the financial devastation wrought by long-term illness or disability.

It is clear that the private market is already responding to the need for long-term care insurance. From virtually no significant activity in this area, firms are rising to the occasion. Clearly, the perception of the need and the willingness to get involved in meeting this challenge is evident. According to an April 1989 General Accounting Office Report, over the past three years, there has been a dramatic increase in the marketing of long-term care insurance. In 1986 there were only 125,000 policies in force; in 1988, there were more than 1 million such policies.

In order to simulate the demand for private market insurance, we suggest that the Commission include the following in its final recommendations to Congress:

1. The Establishment of Individual Medical Accounts or "IMA's."

   The Commission should recommend the adoption of Individual Medical Accounts, commonly referred to as "IMA's." The concept of the Individual Medical Account (IMA) was offered by Dr. Otis R. Bowen, former Secretary of the Department of Health and Human Services as a key component in his comprehensive report, "Catastrophic Illness Expenses," sent to President Reagan in November 1986. The concept has been embodied in various pieces of legislation over the past three years and has been strongly endorsed by Members of Congress on a bipartisan basis.

Like the Individual Retirement Accounts (IRA's) after which they are modeled, the IMA will encourage men and women in their productive years to take direct responsibility for their own future and work to build up a savings account to help meet the expenses of long-term care.

With an IMA an individual worker would be able to put away a certain portion of his or her income in a tax deductible account. Whatever specific limit the Congress should impose on the yearly contribution of tax deductible funds should reflect a careful and comprehensive assessment of the budgetary impact of the provision, in tandem with a prudential mix of various other public and private measures to be included in a set of final recommendations. Such a comprehensive account would take into consideration not only short term revenue losses from the introduction of such a tax deferred account, but also the offsetting savings to Medicaid and other government programs affected by the introduction of such a savings program.

The interest generated from the IMA savings account would also be tax free. Withdrawals from the IMA account would not be subject to penalties if, and only if, the funds were to be used for either one or both purposes. First, withdrawals could be made for the purchase of long-term care insurance policies to supplement the limited benefits now provided by Medicare or any other insurance program. Secondly, to pay for long-term care costs directly, either in the form of home health care, intermediate care in a residential or community home or a nursing home. This range of long-term care services should be as broad as possible for the elderly; for they should, to the maximum extent possible, be permitted to remain in their own homes as long as feasible or, if they choose, "a less restrictive" environment than a custodial nursing home.

Under an IMA option, of course, the central purpose of the savings plan is to secure funding for long-term care. If that savings account is never used for that purpose, the funds in the account should revert to the contributor's estate upon his or her death.

Even with a modest, regular contribution, this targeted personal savings program could reap significant dividends, not only for the investor providing for his own protection, but also for the government attempting to control escalating medical costs; for the widespread investment in "IMA's" would surely rebound to the direct benefit of the already over-burdened Medicaid program. According to the 1986 HHS Report, prepared by Secretary Bowen, "A person saving $1,000 per year (indexed for inflation) from age 40 until age 64 would be entitled to nursing home care at a rate of $50 a day (also indexed) for 25 months. The vast majority (82 percent) of current nursing home stays are no longer than this and most are shorter." (Otis R. Bowen M.D. "Catastrophic Illness Expenses," A Report to the President, November 1986, p. 106.).

2. Encourage Long-term Care as a Component in Employer-Provided Benefits.

Under current law, private employers are able to deduct, for tax purposes, their contributions to the company's pension fund. This tax treatment should also be extended to employers' contributions to long-term care insurance policies This new tax deduction would also stimulate ies. This new tax deduction would also stimulate the demand for and the provision of private long-term care insurance programs.

At the same time, Congress has a legitimate interest in assuring that tax deductibility for such contributions meets the purposes for which it is intended; that tax deductible contributions are made to legitimate insurance programs that are effective in protecting the elderly from the ravages of long-term illness or disability. The Congress could easily couple this deductibility with federally established minimum standards for such policies, not unlike the basic standards that Congress adopted for medigap insurance policies in 1980.

3. Promote the purchase of long-term care insurance by allowing IRA's, 401 K's, or Keough Plans to be used by employees for financing long-term care. In substance employees would be permitted to withdraw funds from IRA accounts or 401 K plans, without penalty, in order to purchase long-term care insurance. This simple change in the tax law could have a positive impact on the private insurance market.

OPTIONS FOR THE ELDERLY

Beyond changes in the structure and functions of Medicaid and the encouragement of the supply and demand of private insurance among working Americans in anticipation of future needs, we would recommend that the Commission promote measures to assist the elderly in the near term to purchase insurance protection for long-term care.

One such measure that deserves serious consideration is the provision of tax credits for the purchase of insurance. Under conventional actuarial scenarios, the financial burdens of the insurance company becomes increasingly greater with the age of the purchasing client. As a result, premiums are higher and, in many cases, out of reach of older Americans who may sorely need extra protection.

While not a panacea, refundable tax credits are another means to stimulate the demand for long-term care insurance for those who are most at risk. Along with the provision of Individual Medical Accounts of "IMA's," the concept of the refundable tax credit was posed by former Secretary Otis R. Bowen in his Report to the President. Specifically, Secretary Bowen recommended a 50 percent refundable tax credit for the purchase of long-term care insurance by any person over the age of 55.

As then Secretary Bowen observed, a refundable tax credit of this sort (with a cap) would directly stimulate the market demand for such insurance and assist in the development of a wide range of sound products and services by the insurance industry. Given that the credit would be directly refundable, it would prove especially attractive to those persons aged 55 and older who are middle income and see a need to protect themselves and their assets against the onset of long-term care expenses.

The American Health Care Advisory Association appreciates the opportunity to present these suggestions for the Commission's consideration. The officers, representatives and staff of AHCAA stand ready to assist the Members of the Commission as they continue their vitally important work over the next several months.

AMERICAN HEALTH CARE
ADVISORY ASSOCIATION

Dear Reader:

This packet of material has been prepared to give you a better understanding of the American Health Care Advisory Association (AHCAA). Although AHCAA is not a household word yet, it has enjoyed a dynamic growth over the past six years.

The American Health Care Advisory Association is a nonprofit association dedicated entirely to serving its members and enriching their lives. Founded in 1981, AHCAA offers a variety of benefits to its members who live all across our great nation. The benefits offered to AHCAA members can be grouped into two major categories, those designed for improving your health and those which will help members enjoy a better lifestyle. Some of the benefits include Hospital Discounts, Prescription Drug Program, Optical Services, Dental Insurance and Air Ambulance services.

AHCAA has a continuing commitment to the well being of its members and has expanded its personal services benefits, which include legal services program, Leisure Travel Club and the Shop at Home Network. By improving the quality of life today, AHCAA hopes to reduce medical costs tomorrow.

The other major component of AHCAA is its Foundation Grant Program which provides grants for health research and health education programs. The AHCAA Foundation Grant Program has awarded over $1 million in the past few years to worthy recipients involved in health research and health education. Some of the recipients include: American Medical Association, American Health Association, National Kidney Foundation and the Leukemia Society of America, to name a few.

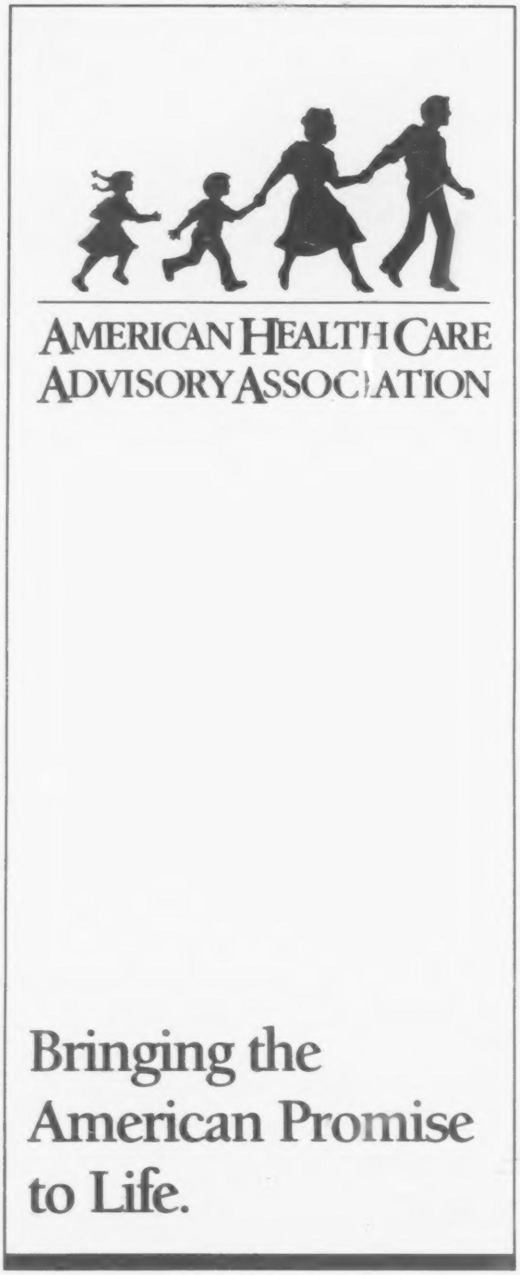
There is no greater challenge facing the nation than health care. AHCAA is proud of its role and past contributions in helping thousands of Americans meet this challenge.

If you would like more information on AHCAA or have additional questions, please write to me or call. I would like to hear from you.

Sincerely,

Richard H. Smith

Administrative Center
777 Main Street
Suite 1600
Ft Worth, Texas 76102
1-800-232-4222



AMERICAN HEALTH CARE
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Bringing the
American Promise
to Life.

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Advisory Association

Mr Richard Smith, President of the American Health Care Advisory Association, (left) and Dr Donovan F Ward, Chairman of the American Health Care Advisory Association Foundation, (right) on the steps of the U.S. Capitol in Washington, DC

AMERICAN HEALTH CARE
ADVISORY ASSOCIATION

American Health Care Advisory Association Foundation Board Members

▶ ***Donovan F. Ward M.D.*** Dr. Ward became a national director for the American Health Care Advisory Association in 1982 and today is president and chairman of the American Health Care Advisory Association Foundation. Dr. Ward is a graduate of the University of Iowa College of Medicine. As well as serving in a private practice, Dr. Ward was a surgeon for the U.S. Naval Reserve Medical Corps and was a U.S. Public Health Service Designated Physician from 1956 to 1980.

During his extensive career in medicine, Dr. Ward served as president of the medical staff at Finley Hospital in Dubuque, Iowa in 1936. He also served on its Executive Committee, Audit Committee, Utilization Review Committee and has been an honorary member of the board of directors since 1980. Dr. Ward was also affiliated with Mercy Medical Center in Dubuque as a senior surgeon, member of the Surgical Audit Committee, and as secretary of the surgical section. In addition, Dr. Ward served as a consulting surgeon to the Xavier Hospital in Dubuque. He was a member of the advisory board of the Medical Air Service from 1985 to 1988 and has been a member of the foundation board of directors at the Wendt Regional Cancer Center since 1987. Dr. Ward served as president of the American Medical Association and as president of the Dubuque County Medical Society, as well.

▶ ***Denis J. Fu, M.D.*** Dr. Fu is a graduate of the University of Dayton and Tulane Medical School. Since 1968 Dr. Fu has been a practitioner with the Maui Medical Group in Wailuku, Maui, Hawaii. From 1962 to 1966 Dr. Fu practiced in Honolulu, Hawaii and was also a Pediatric Instructor at St. Francis Hospital also in Honolulu. Dr. Fu served as the chief of pediatrics at Maui Memorial Hospital from 1969 to 1971.

▶ ***Bernard P. Harrison, J.D.*** Mr. Harrison is a graduate of the University of Illinois and of DePaul University College of Law. He is an attorney with private practice experience in Chicago and is licensed in Illinois and before the federal courts and the U.S. Supreme Court. From 1961 to 1981, Mr. Harrison provided legal, legislative and administrative services to the American Medical Association (AMA), for the last six years as a Group Vice President of the AMA. In 1971 he developed a jail health care program for the AMA. The program encouraged the involvement of medicine in correctional health care problems and resulted in the initiation of the first accreditation program for correctional facilities. In 1981, Harrison retired from the AMA to establish, with the support of the AMA, an independent group to continue the correctional health care program. Mr. Harrison also serves as the president of the National Commission on Correctional Health Care.

▶ ***Joseph W. Lawrence, M.D.*** Dr. Lawrence graduated from the University of Dubuque and the University of Iowa College of Medicine. From 1938 to 1954 Dr. Lawrence was a general practitioner in Cincinnati, Ohio. Dr. Lawrence served as county public health director and deputy state health officer for the state of Florida from 1954 to 1957. Until 1960 Dr. Lawrence was director of Lee and Collier County Health Department in Fort Myers, FL, and from 1960 to 1986 he was director of Lee County Health Department exclusively. Dr. Lawrence has been a member of the AMA, Southern Medical Association, the American Public Health Association and the Florida Public Health Association.

▶ ***Samuel R. Sherman, M.D.*** Dr. Sherman is a graduate of the University of California and University of California Medical School. Dr. Sherman practiced medicine and surgery from 1933 to 1942 and 1946 to 1970. From 1942 to 1946 Dr. Sherman was in the U.S. Naval Reserve (M.C.) and retired as captain. He was awarded the Navy Cross and two Purple Hearts. Presently he is the cancer coordinator for Northern California at the University of California. Dr. Sherman is a member of the San Francisco Medical Society, the California Medical Association and the American Medical Association.

AMERICAN HEALTH CARE
ADVISORY ASSOCIATION

Richard H. Smith
President

As president of the American Health Care Advisory Association, Mr Richard Smith brings to the organization over 12 years of management and marketing experience in the health care industry and was formerly vice president of marketing for Dr Denton A. Cooley, at the Texas Heart Institute in Houston, Texas. Mr Smith has a B.B.A. in finance from the University of Texas in Arlington and a M.S. in health care administration from Trinity University in San Antonio, Texas. Mr Smith has a professional affiliation with the American Marketing Association, the American Society of Association Executives and the Sales & Marketing Executives Association.

Tim Dale
National Marketing Director

Mr Dale has over 25 years of management, marketing and sales experience in the health care, insurance and association fields. In 1981 he initiated discussions with Dr Donovan Ward and other prominent members of the business community which led to the formation of AHCAA. Since that time, Mr Dale has operated his own consulting and marketing firm in the financial service and association arena until joining AHCAA as national marketing director in 1988.

AMERICAN HEALTH CARE
ADVISORY ASSOCIATION

AHCAA'S Contributions to Meeting America's Health Care Needs

Over the past eight years, the American Health Care Advisory Foundation has awarded over $1 million to promote health research and health education. The foundation is proud of its contributions and affiliations with the following grantees:

Alzheimer's Disease & Related Disorders Association
American Cancer Society
American Heart Association
American Medical Association
American Public Health Association
Atlanta Sports Carnival/ALR
California Medical Education & Research Foundation
Leukemia Society of America—Maryland Chapter
Leukemia Society of Dallas/Ft. Worth
March of Dimes
Memorial Sloan-Kettering Cancer Center
Mount Zion Hospital for Aging
Multiple Sclerosis Society
National Jewish Center for Immunology & Respiratory Medicine & The Children's Hospital
National Kidney Foundation
National Leukemia Society of America—Televent National
National Multiple Sclerosis Society
St. Jude Children's Research Hospital
The Will Sampson (SAMSOGEE) Transplant Foundation
Tulane University Medical School for Pediatric Cardiology Research
University of Arizona Foundation
University of California USCF, Dept. of Cardio-Vascular Research
University of Dubuque, Advancement of Science Studies
University of Iowa College of Medicine
University of Texas, M.D. Anderson Hospital & Tumor Institute
University of Utah
Wendt Regional Cancer Center of the Finley Hospital

AHCAA JOINS LEUKEMIA SOCIETY TELEVENT AS A $25,000 NATIONAL CORPORATE SPONSOR

On behalf of the AHCAA Foundation we are very pleased to be a National sponsor of the Leukemia Televent 1989.

I would encourage everyone to contribute to this worthy cause.

Your contribution to leukemia research will not only aid leukemia victims now but will also help to stamp out this dreaded disease for future generations.

Donovan F. Ward, M.D.
Dr. Donovan Ward

Dr. Donovan Ward, National Director of AHCAA, will travel to Los Angeles, Ca. to appear on the Leukemia Society's "6 HOURS FOR LIFE" Televent broadcast in 50 cities nationwide on the weekend of August 5th and 6th. Dr. Ward's interview will include the presentation and recognition of contributions from the Foundation, from AHCAA members collectively . . . and will recognize several individual donations drawn from those received through the HEALTH GRAM pledge form below. Your name could be announced on national TV.

Hollywood talent including Shirley Jones, Peter Marshall, Steve Allen, Vicki Lawrence and Michael Gross of "Family Ties" will be joining in the Televent to help make it a success. Check your local listings for the date and time in your area so you will be a part of "6 HOURS FOR LIFE."

The Televent (telethon) will provide funds to support and expand the work of research scientists sponsored by the Leukemia Society. Twenty years ago there was no effective treatment for leukemia, but today – thanks to advances in research – 50-80% of children with the most common form of the disease . . . WILL BE CURED. For every child, there are eight adults battling leukemia, and the outlook for these patients must be improved.

We hope you will complete the AHCAA pledge form below and join in supporting this effort to conquer leukemia and other forms of cancer one day, one family . . . and one patient sooner. GOOD HEALTH IS A GIFT.

Please return with your contribution by July 10th to:

Enclosed is my ☐ personal or ☐ corporate check to the Leukemia Society
in the amount of ☐ $5 ☐ $10 ☐ $25 Other $______

CHECK (✓) ONE ☐ VISA ☐ MASTERCARD	ACCOUNT NO	EXPIRATION DATE

Name

Company

Street Address

City State Zip

______ I would like to become involved with the Leukemia Society locally.

Please have a representative contact me at (______)______

AMERICAN HEALTH CARE ADVISORY ASSOCIATION
1160 Rockdale Rd
Dubuque, Iowa 52001

leukemia society of america

AMERICAN HEALTH CARE
ADVISORY ASSOCIATION

NewsRelease

FOR IMMEDIATE RELEASE

CONTACT:

NATIONAL JEWISH RECEIVES GRANT FROM HEALTH CARE ASSOCIATION

DENVER -- Michael K. Schonbrun, president of National Jewish Center for Immunology and Respiratory Medicine, announced the receipt of a $5,000 grant from the American Health Care Advisory Association Foundation (AHCAAF).

On learning of the gift, Schonbrun expressed thanks to AHCAAF President Donovan F. Ward, M.D., praising AHCAAF as "an organization cognizant of the need to support ongoing respiratory and immune system disease research. With lung disease now the fastest-rising cause of death in the country, and the importance of the immune system in combating all illnesses, this kind of support is an essential weapon in the fight against serious national health problems."

AHCAAF is a nonprofit, national organization dedicated to the promotion of better health and health care. It supports vital medical research and provides a full range of medically-related services. Among the other benefits provided by AHCAAF are hospital discounts at numerous local facilities to offset deductibles for medical insurance, optical and dental programs, a prescription drug program and free air ambulance service.

For more information about the AHCAAF program, call the Denver Regional Office at (303) 394-4000.

AMERICAN HEALTH CARE ADVISORY ASSOCIATION

Name ______________________

Cholesterol Level ______________
(below 200mg/dl)

HDL Level ("Good")______________
(above 35mg/dl)

Glucose Level ______________
(76-110mg/dl)

Triglycerides Level ______________
(Males: 40-160mg/dl)
(Females: 35-135mg/dl)

Professional
Cholesterol
Screening
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"Specializing in Corporate and Public Health Screenings"

What is Cholesterol?

Pure cholesterol is an odorless, white, waxy, powdery substance. You cannot taste it or see it in the foods you eat.

Cholesterol is found in all foods of animal origin and is part of every animal cell. Your body uses cholesterol to make essential body substances such as cell walls and hormones, as well as for various other functions. Even if you didn't eat any cholesterol, your lever would manufacture enough for your body's needs.

Cholesterol is like other fat-like substances in that it will not mix with water. therefore, to carry cholesterol and fat ("lipid") in the blood, the body wraps them in protein packages. This combination is called a "lipoprotein." Blood cholesterol is found in all the major lipoproteins, including the low density lipoproteins (LDLs) and the high density lipoproteins (HDLs).

Triglycerides

Another kind of lipid (blood fat). It is the main type of lipid found in the fat tissue of the body and also the main type of fat found in foods. Elevated triglyceride levels can be reduced by weight loss, increased physical activity, and reduced intake of saturated fats.

Glucose

High blood sugar or glucose could be indicative of diabetes. Inability to maintain normal blood level for glucose could be an indication of an insulin deficiency.

HDL...the "Good" Cholesterol

HDLs are the high density lipoproteins. HDLs contain the greatest amounts of protein and small amount of cholesterol. They are believed to take cholesterol away from cells in the artery wall and transport it back to the liver for reprocessing or removal from the body. Researchers have noted that persons with higher levels of HDL have less heart disease. Thus HDLs have become known as the "good" cholesterol.

LDL...the "Bad" Cholesterol

LDLs are the low density lipoproteins that contain the greatest amounts of cholesterol and may be responsible for depositing cholesterol in the artery walls. For that reason they are sometimes known as "bad" cholesterol.

TOTAL CHOLESTEROL LEVELS

<200 mg/dl	Desirable Blood Cholesterol
200-239 mg/dl	Borderline - High Cholesterol
≥240 mg/dl	High Risk

LDL CHOLESTEROL LEVELS

<130 mg/dl	Desirable Blood Cholesterol
130-159mg/dl	Borderline - High Cholesterol
≥160mg/dl	High Risk

CALCULATE YOUR "RATIO"

To calculate your ratio of HDL ("good") cholesterol to total:

Total ______ ÷ HDL______ = Ratio_______

Recommended Ratio: Below 4.5

CALCULATE YOUR LDL

CHOL________ – HDL _________ = _______

—

TRIG _______ ÷ 5 = _______

LDL _______

EXAMPLE:

CHOL 200 – HDL 40 = 160

—

TRIG 70 ÷ 5 = 14

LDL 146

WHAT SHOULD YOUR NEXT STEP BE?

Now that you understand your risk and its seriousness, you should take whatever steps are necessary to control your blood cholesterol level.

If you tested below 200 mg/dl, congratulations. It is recommended that your blood cholesterol level be tested annually, as blood cholesterol levels change over time. You would be wise to watch your food intake as described in this booklet.

If you tested above 200 mg/dl but below the moderate risk level for your age, change your diet enough to lower your level to 200 mg/dl. Take another test in a few months.

If you have a moderate or high risk level, consider changing your diet immediately and *see your doctor within four weeks*. The doctor will recheck your blood cholesterol level and help you work out a program to reduce it. Reduce your intake of saturated fats as much as possible, and lose weight. the two usually go hand-in-hand, as most foods low in saturated fats are also low in calories.

Are all fats the same?

No. There are saturated fats, polyunsaturated fats, and monounsaturated fats. Saturated fats are the ones to avoid.

Saturated fats are oils from animal products as meat fat, butter, and cream. Saturated fats also come from some plant oils - those that are solid rather than liquid at room temperature, such as coconut oil, palm oil, and hydrogenated oils. Saturated fats raise your blood cholesterol level and increase your risk of heart disease.

Polyunsaturated fats are oils from vegetable products. These oils are liquid at room temperature, not solid, such as safflower oil, corn oil, and sunflower oil. Used moderately, these fats help lower your blood cholesterol level. The key to changing your diet is to substitute these fats for saturated fats.

Monounsaturated fats are oils from such vegetable products as olives and peanuts. Like polyunsaturated fats, they may - when used in moderation - help lower blood cholesterol levels.

What foods are high in saturated fats?

These are some of the most commonly eaten foods that are high in saturated fat:

Foods High in Saturated Fat	Saturated Fat Calories
Beef	
Round steak	7/oz.
Roast	11/oz.
Porterhouse steak	13/oz.
Ground beef, lean	25/oz.
Whole milk	45/cup
Most cheeses	50/oz.
Hot Dogs	60/frank
Lunchmeats	30/oz.
Doughnuts	11-24/doughnut
Cake	8-16/slice
Pork	
Chops	14/oz.
Ham	4-13/oz.
Sausage	26/oz.
Bacon	45/oz.
Butter	64/tbsp.
Ice Cream	80/cup
Fried potatoes	25/10 strips
2% Milk	27/cup
Potato chips	19-30/oz.
Nondairy coffee creamer (Coconut oil)	26/oz.

What foods are low in saturated fats?

Eating these foods, among others, to replace high foods can help lower your blood cholesterol level:

Foods Low in Saturated Fat	Saturated Fat Calories
Fruit	0-1
Vegetables	0-1
Turkey breast, roasted, baked, broiled without skin	1/oz.
Chicken breast, roasted, baked, broiled without skin	3/oz.
Fish, broiled, baked, poached	0.3-5/oz.
Skimmed milk	0
Low fat yogurt	3/8 oz.
1% Cottage cheese	6/half cup
Safflower oil	11/tbsp.
Corn oil	15/tbsp.
Olive oil	16/tbsp.

FACTS ABOUT CHOLESTEROL

** Coronary heart disease is the number one cause of death in the United States, outnumbering deaths from cancer and accidents combined.*

** Every minute, an American suffers a heart attack.*

** For 50 percent of them, the first heart attack results in death.*

** High blood cholesterol is often referred to as "The Silent Killer" - it has no symptoms.*

** Over half of the American people have a high cholesterol level.*

** 9 out of 10 people can reduce their number by diet alone.*

** A total cholesterol level below 200 mg/dl, and an HDL level above 35 mg/dl is recommended safe according to the National Institute of Health.*

** 55% of the U.S. Population have cholesterol levels below 200 mg/dl.*

** 15% of heart attacks occur in people with cholesterol levels below 200 mg/dl.*

** Experts agree that levels of HDL under 35 mg/dl are a major risk factor for heart disease.*

** Of males, under 200 mg/dl, 68% have HDL levels under 35 mg/dl.*

** Of females, under 200 mg/dl, 32% have HDL levels under 35 mg/dl.*

The good news is that you can now do something about it, so...

KNOW YOUR NUMBERS!

BARBARA BUSH'S HIGH-FIBER BRAN MUFFINS

(Makes 1 1/2 Dozen)

2 1/2 cups whole-wheat flour
3 cups miller's bran
1 teaspoon salt
1 tablespoon baking powder
1 cup raisins
5 eggs
1 cup honey
1 pint skim milk
1/2 cup safflower oil
1 teaspoon pure vanilla extract

In bowl mix flour, bran, salt, baking powder, and raisins. Add remaining ingredients and stir until blended. Spoon into lightly greased muffin pan and bake at 375° F, 20 minutes or until muffin tests done.

CHILDREN AND CHOLESTEROL

IT'S NOT A NEW PROBLEM. It's not even uncommon. The fact is that some 30% of American children have abnormally high serum cholesterol levels - that's nearly one out of three. Left untreated, these kids are at increased risk of developing coronary heart disease later in life. More often than not, the culprit is diet.

THE AVERAGE AMERICAN CHILD EATS TOO MUCH FAT AND CHOLESTEROL.
Way too much. The American Health Foundation recommends that children over two limit fat intake to 30% of total calories with saturated fat accounting for no more than 10%. Cholesterol should not exceed 300 mgs. per day.

AS A PARENT, YOU NEED TO SET A GOOD EXAMPLE. Try to restrict fatty and fried foods. Opt instead for lean meats and fish, low-fat dairy products, whole grain breads and cereals. For snacks, fresh fruits and vegetables are always a good bet.

YOU CAN BEGIN AT BREAKFAST: Whole grain cereal, skim milk, toast, fresh fruit - you get the idea. We encourage you to ask your doctor because the best thing you can give your kid is a good start.

AMERICAN HEALTH CARE
ADVISORY ASSOCIATION

The American Health Care Advisory Association Foundation's ongoing commitment to supporting medical education and medical research benefits all Americans.

The Foundation has contributed Hundreds of thousands of dollars to such worth organizations as the American Leukemia Society, American Heart Association, and the Multiple Sclerosis Society to name a few.

The efforts of the foundation is another outstanding example of how AHCAA is:

Bringing The American Promise to Life.

RECEIPT

Test	CPT Code
Cholesterol	82465
HDL	83718
Glucose	82947
Triglycerides	84478

Date __________ Amount____________

Location ____________________________

Cystic
Fibrosis
Foundation

STATEMENT OF MR. ROBERT K. DRESING,
PRESIDENT AND CHIEF EXECUTIVE OFFICER OF THE
CYSTIC FIBROSIS FOUNDATION,
WASHINGTON, D.C.

BEFORE THE
PEPPER COMMISSION

REGARDING OPTIONS AND FINANCING FOR
LONG-TERM CARE

OCTOBER 5, 1989

SUMMARY OF TESTIMONY

Individuals with cystic fibrosis (CF) face numerous problems in meeting their health care needs. Their difficulties include:

1) exorbitant cost for medical care, as much as $100,000 per patient per year;
2) barriers precluding them from purchasing private health insurance due to pre-existing condition clauses and unaffordable premiums.
3) extremely strict guidelines for Supplemental Security Income (SSI) in determining children who are eligible for benefits;
4) compounded problems for adults with CF who face further barriers in obtaining and maintaining jobs with good health benefits, and a frequent inability to purchase private insurance due to pre-existing condition clauses or unaffordable premiums.

Our specific recommendations include:

1) increasing funding for medical research in order to develop new treatments to reduce the cost of care;
2) enhancing access to private health insurance for children and young adults with pre-existing health conditions;
3) mandating reasonable and affordable health insurance premiums;
4) implementing more appropriate eligibility guidelines for SSI;
5) increasing funding for the Maternal and Child Health Block Grant to improve the health care for needy mothers and children and to enhance public assistance for adults with CF;
6) enhancing responsiveness of prospective payment systems to address the needs of adults with CF.

Foundation Office
6931 Arlington Road Bethesda, Maryland 20814
(301) 951-4422 1-800-FIGHT CF

Dear Mr. Chairman and Members of the Commission:

On behalf of the Cystic Fibrosis Foundation, I want to thank you for the opportunity to submit testimony on improving access to health care for individuals with disabilities, particularly those with cystic fibrosis (CF). I offer my observations as the president and chief executive officer of the Foundation, but more importantly, as the parent of a twenty-two-year-old son with cystic fibrosis.

We are pleased that the Pepper Commission is investigating options to improve the current methods for financing health care. We would like to address various problems in obtaining health care today and suggest potential solutions in the public and private sectors that will enable people with CF and other disabilities to meet their health care needs at a reasonable cost.

HOPE FOR THE FUTURE -- BETTER TREATMENTS, REDUCED COST FOR CARE

First of all, we would like to emphasize the importance of medical research in improving the health care treatments for people with chronic illnesses and reducing the cost of care.

Research advances offer hope that cystic fibrosis -- a fatal, genetic disease which impairs breathing and digestion -- will be eradicated. In particular, the recent milestone achieved with the discovery of the CF gene will enable scientists to explore new methods to treat the primary problems caused by this gene. Up until now, treatments have focused on fighting the effects of the thick mucus in the airways and in the digestive tract, particularly the repeated infections which damage the lungs and ultimately lead to death.

Already, improvements in treatments have brought about substantial changes in the lives of people with CF by extending the median life expectancy from preschool to young adulthood. With the discovery of the CF gene, the possibilities for further enhancing and extending the lives of people with CF are tremendous.

Recommendation

No plan to improve the federal government's role in health care can be discussed without stressing the need for increased funding for biomedical research. We ask you to continue and to strengthen support for research into cystic fibrosis through the National Institutes of Health. Vital research dollars can now concentrate on the search for a control or cure for CF which will ultimately reduce federal spending on health care.

CYSTIC FIBROSIS -- THE TRAUMA OF FINANCING HEALTH CARE

A Brief Overview

In contrast to the incredible progress in medical research, options for people with CF to finance their comprehensive and long-term health care needs have not improved.

The CF treatment regimen consists of up to 60 pills a day to aid digestion and prevent or control deadly lung infections, combined with daily physical therapy where children are clapped on the back and chest in various positions to dislodge the sticky mucus. With one or more two-week visits to the hospital each year for intensive antibiotic therapy and ongoing outpatient visits, the average patient can face some $20,000 annually in medical bills. Hospital visits, medications, and use of oxygen increase as the disease progresses, bringing families $100,000 yearly medical bills that haunt their lives now and shape future lives of poverty. The magnitude of this health care burden is evident in the estimated $300 million bill that these families are somehow supposed to pay each year.

BARRIERS IN PURCHASING PRIVATE HEALTH INSURANCE

People with CF continue to face grave difficulties in obtaining public assistance or private health insurance. According to our Patient Registry, which surveys treatments for the 15,000 patients with CF followed by our care centers, we know that approximately 8,000 people with cystic fibrosis have successfully purchased some form of private health insurance. Yet, even these families are unable to meet all of their children's health needs due to inadequate insurance coverage and unmanageable out-of-pocket costs.

Problem: Pre-existing Health Conditions Preclude Health Insurance Coverage

Many policies have pre-existing condition clauses that do not provide coverage for certain health conditions, including CF. Since children are born with cystic fibrosis, they do not have the luxury of joining a good insurance plan and then developing this disease. Instead, the "pre-existing condition" label is attached to them upon diagnosis, even though their health may be fairly good for years.

Recommendation

We encourage the Commission to propose methods to remove this inequitable barrier so that people with pre-existing health conditions can purchase coverage for their health needs

Problem: Affordability of Health Insurance Premiums

New insurance plans, such as pooled risk health insurance, are available in select states to cover people with pre-existing health conditions. However, individuals must be prepared to pay extremely high premiums, such as $1000 a month, to insure themselves against impending financial catastrophe as a result of health problems.

Recommendation

Any new insurance plans must provide affordable premiums for individuals who are caught between the exorbitant costs of available private insurance and the total poverty required to qualify for many government programs.

GOVERNMENT PROGRAMS ACTING AS PHYSICIAN

Without adequate access to health care, many individuals may forego receiving care, allowing their health to progressively deteriorate rather than face insurmountable financial debts. Finding closed doors in the private insurance industry because of their diagnosis or their inability to pay exorbitant premiums, many individuals with CF turn to public assistance programs, such as Medicaid, Supplemental Security Income, or Children with Special Health Needs, for help.

The amount of public assistance people are able to obtain depends significantly on the program's eligibility requirements and reimbursement policies. These policies may determine the amount of care the individual is able to receive, essentially acting as the physician in identifying what type of care is necessary and should be reimbursed.

Problem: Inappropriate Eligibility Guidelines for SSI

One example of unrealistic criteria for eligibility is the disability guidelines for Supplemental Security Income (SSI). This program requires total disability in its applicants, yet does not adequately assess children applying for this program to determine disability. Currently, only fourteen percent of people with CF receive assistance from this program.

Sometimes, if children appear to meet these requirements, they are still ineligible for benefits. Consider, for instance, the case of a young girl who has been denied benefits despite having CF, diabetes, asthma and scoliosis. Although none of her disabilities have met the Social Security Administration's guidelines for disability by themselves, the overall impact of these conditions on her life is truly disabling.

Recommendation

The SSI program should be revised to enable children with CF to receive a more appropriate assessment of their functional abilities, according to pending legislation. This would enable them to receive vital assistance from SSI when they rightfully deserve it.

Problem: Limited Support through Federal Block Grants

Many families do not meet the strict eligibility guidelines for SSI or Medicaid, yet they are still in need of assistance. Through the federal block grant, Children with Special Health Needs provides some assistance with medical bills to thirty-four percent of people with CF, yet this assistance is often insufficient.

Recommendation

Funding of the Maternal and Child Health (MCH) Block Grant, which includes support for Children with Special Health Needs, must be increased to better ensure the health of needy mothers and children. This support would enhance health care services for needy families who are ineligible for other federal programs, such as Supplemental Security Income and Medicaid, but who cannot afford to purchase adequate health insurance.

ADULTHOOD -- INDEPENDENCE AT A PRICE

Upon reaching adulthood, a true feat for individuals with a median lifespan of 25 years, adults with CF face problems similar to families trying to obtain financial assistance with medical bills. However, many of their problems are compounded by their increasing age and independence.

Adults with CF may face rejection from employers that refuse to hire them for fear of an increase in premiums on their group health insurance plans. Yet, they find that purchasing individual insurance policies is rarely an option. According to the results of a recent Foundation survey, all responding adults with CF had difficulty purchasing health insurance, with over half of them experiencing problems buying individual coverage.

Problem: Lack of Insurance Options for Adults with CF

With an increase in the number of adults who have the potential to become independent, the need to ensure access to private health insurance is growing. Yet, pre-existing condition clauses still stand in the way. In addition, young people struggling to survive as independent adults are often unable to afford exorbitant premiums necessary to purchase insurance through pooled risk health insurance plans. Furthermore, their special health needs may preclude them from working full time at a job with health benefits.

Recommendation

Individual insurance policies that cover health needs for pre-existing conditions must be made available and affordable to young adults with CF.

Problem: Inadequate Public Assistance for Adults with CF

Public assistance is less available for adults with CF than for children. Currently, only twenty eight states provide assistance to adults with CF through special Over-21 Programs. Many of these programs are part of the Children with Special Health Needs programs, extending benefits for children with CF to adults facing the same chronic health problems.

Recommendation

Impetus must be given to more states to provide financial assistance for adults with CF to enable them to continue receiving necessary health care. One way to achieve this is to increase funding through the Maternal and Child Health Block Grant, designating support for the development and enhancement of assistance options for adults living with cystic fibrosis.

Problem: Unresponsiveness of Prospective Payment System to Needs of Adult Patients with CF.

Children with CF have obtained an exemption through the prospective payment system for CHAMPUS so that they are not placed in a specific reimbursement category, or diagnosis-related group (DRG). This special exemption now allows children with CF to receive appropriate care under CHAMPUS, as the adequacy of reimbursement is not questioned. However, young adult patients have not received this assistance through Medicare. As a result, hospitals that routinely care for people with CF may be discouraged from treating adult patients for fear of high, unreimbursed costs. This could become an even more serious problem as private insurance companies and perhaps public assistance programs begin to use DRGs to contain costs.

Recommendation

The Prospective Payment System for Medicare must appropriately address the health needs of all patients with CF to avoid potential reimbursement problems which can lead to inadequate health care. Recognizing and meeting the necessary costs to treat patients with CF of all ages would ensure access to vital health care treatments.

SUMMARY

These problems forcefully illustrate that changes are vitally needed in expanding public and private methods of financing health care for people with CF.

We ask the Pepper Commission to consider eliminating the gaps in current public and private financing programs for people with disabilities to enable all individuals to obtain appropriate health care.

Our specific recommendations include:

1) increasing funding for medical research in order to reduce the cost of care;
2) enhancing access to private health insurance for children and young adults with pre-existing health conditions;
3) mandating reasonable and affordable health insurance premiums
4) implementing more appropriate eligibility guidelines for SSI;
5) increasing support of the Maternal and Child Health Block Grant to improve the health care for needy mothers and children and to enhance public assistance for adults who continue to suffer from CF;
6) enhancing responsiveness of prospective payment systems to needs of adults with CF.

We thank you, Chairman Rockefeller, for your recognition of the need for improved access to comprehensive and long-term health care for all Americans, including children and young adults with disabilities. We support your efforts to find a solution that will make health care accessible to every American. We offer any further assistance you may request as you prepare your recommendations.

SOUTH CAROLINA
LONG TERM CARE COUNCIL

Testimony Before the U.S. Bipartisan Commission on Comprehensive Health Care

Washington, D.C.

October 5, 1989

TESTIMONY OF THE SOUTH CAROLINA LONG TERM CARE COUNCIL

AS PROVIDED BY RUTH SEIGLER

EXECUTIVE DIRECTOR - SOUTH CAROLINA COMMISSION ON AGING

MR. CHAIRMAN, DISTINGUISHED MEMBERS OF THE U.S. BIPARTISAN COMMISSION, AND LADIES AND GENTLEMAN, IT IS AN HONOR FOR ME TO BE HERE TODAY TO SPEAK WITH YOU ON AN ISSUE THAT IS CERTAINLY ONE OF THE MOST SIGNIFICANT CONCERNS THIS COUNTRY IN FACING TODAY. THE SOUTH CAROLINA LONG TERM CARE COUNCIL APPRECIATES YOUR KIND INVITATION TO ADDRESS THE PEPPER COMMISSION FOR LONG TERM CARE AND THE NEED FOR LONG-TERM CARE AFFECTS ALL OF US IN THIS ROOM; WHETHER IT IS PROVIDING CARE FOR OUR PARENTS OR A DISABLED CHILD, OR AS WE, OURSELVES, GROW OLDER, AND BEGIN TO SEEK SUCH SERVICES. THE SOUTH CAROLINA LONG TERM CARE COUNCIL IS COMMITTED TO FINDING SOLUTIONS TO THE MYRIAD PROBLEMS OF PROVIDING A CONTINUUM OF CARE FOR OUR STATES ELDERLY AND HOPEFULLY, THROUGH THIS TESTIMONY, WILL CAN CONTRIBUTE TO THE OVERALL NATIONAL PICTURE.

MR. CHAIRMAN, THE LONG TERM CARE COUNCIL OF SOUTH CAROLINA WAS FORMULATED IN 1978 FOR THE PURPOSE OF DEVELOPING A STATEWIDE LONG TERM CARE MANAGEMENT SYSTEM WHICH INCORPORATED PRE-ADMISSION ASSESSMENT, CASE MANAGEMENT SERVICE AND CONTINUED OVERSIGHT INTO THE SYSTEM. THAT PROJECT, KNOWN AS THE COMMUNITY LONG TERM CARE PROJECT, IS TODAY A VERY SUCCESSFUL AND HIGHLY POPULAR ALTERNATIVE PROVIDING HOME AND COMMUNITY BASED SERVICES TO NURSING HOME INSTITUTIONALI-

ZATION IN SOUTH CAROLINA. IN 1984, THE COUNCIL'S ROLE WAS EXPANDED INTO OTHER AREAS OF LONG TERM CARE AND IN 1987, THE SOUTH CAROLINA GENERAL ASSEMBLY APPROVED A LAW MAKING THE LONG TERM CARE COUNCIL AN OFFICIAL STATE ENTITY WITH THE CHARGE TO IDENTIFY FUTURE POLICY ISSUES IN LONG TERM CARE, CONDUCT RESEARCH AND DEMONSTRATIONS RELATED TO THOSE ISSUES AND TO DEVELOP RECOMMENDATIONS FOR A STATEWIDE SERVICE DELIVERY SYSTEM FOR ALL HEALTH IMPAIRED PERSONS IN SOUTH CAROLINA. IT IS FROM THIS BACKGROUND, THAT COUNCIL TODAY CAN SPEAK WITH AUTHORITY ABOUT THE SITUATION OF LONG-TERM CARE IN OUR STATE.

OUR COUNCIL IS MADE UP OF TWELVE MEMBERS INCLUDING THE GOVERNOR'S OFFICE, THE EXECUTIVE DIRECTOR OF THE STATE HEALTH AND HUMAN SERVICES FINANCE COMMISSION AND MY AGENCY, THE COMMISSION ON AGING, THE COMMISSIONERS OF THE DEPARTMENT OF MENTAL HEALTH, THE DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL, THE DEPARTMENT OF SOCIAL SERVICES, AND THE DEPARTMENT OF MENTAL RETARDATION, WITH REPRESENTATIVES OF THE SOUTH CAROLINA GENERAL ASSEMBLY WITH THREE GUBERNATORIAL APPOINTEES.

MR. CHAIRMAN, THE SOUTH CAROLINA LONG TERM CARE COUNCIL IS REFLECTIVE OF THOSE AGENCIES IN OUR STATE WHICH DELIVER AND FINANCE LONG-TERM CARE AND AS A GROUP ARE IN THE MOST ADVANTAGEOUS POSITION TO OFFER THE COMMISSION A COHERENT PICTURE OF THE NEEDS OF THE LONG-TERM CARE DELIVERY SYSTEM AND THE RESULTING DESIRED POLICY DIRECTIONS IN WHICH THE COUNCIL IS SUGGESTING TODAY.

BECAUSE OF THE LIMIT ON OUR TIME, MR. CHAIRMAN, I WILL NOW PROVIDE FOR YOU A SHORT SYNOPSIS OF STATE DEMOGRAPHICS PLUS THE RECOMMENDATIONS OF THE LONG TERM CARE COUNCIL AND I WILL SUBMIT MORE DETAILED TESTIMONY FOR THE RECORD WHICH ACCURATELY SPELLS OUT THE COUNCILS' INTENTIONS AND JUSTIFICATIONS. I WOULD NOTE HERE THAT THE LONG TERM CARE COUNCIL BEGAN ANALYZING PROPOSED LEGISLATION FROM THE 100TH CONGRESS AND BEGAN TO SURVEY EACH FOR PROGRAM, POLICY AND FISCAL IMPACT TO EACH AGENCY AND TO RESPECTIVE PROGRAMS. AS A REACTION TO THE FIVE MAJOR INITIATIVES IN CONGRESS AT THAT TIME, THE LONG TERM CARE COUNCIL HAS FORMULATED RECOMMENDATIONS WHICH ARE THE MOST DESIRABLE IN TERMS OF SOUTH CAROLINA'S CURRENT DELIVERY SYSTEM. LET ME SAY AT THE OUTSET, THAT ANY LONG-TERM CARE BENEFIT WILL REPRESENT AN EXPANSION IN TERMS OF THE NUMBER OF PEOPLE PROVIDED LONG TERM CARE IN SOUTH CAROLINA AS WELL AS INCREASE COSTS TO THE STATE. THE FOLLOWING RECOMMENDATIONS ARE AGAIN, A RESPONSE, AND A CONCERTED EFFORT TO PROVIDE SOUTH CAROLINA'S DESIRED POLICY GOALS IN LIGHT OF THE INITIATIVES PREVIOUSLY CONSIDERED BY THE 100TH CONGRESS.

MR. CHAIRMAN, SOUTH CAROLINA IS A SMALL STATE WITH JUST OVER 3.4 MILLION RESIDENTS. IT IS ESTIMATED THAT IN 1987, SOUTH CAROLINA'S ELDERLY POPULATION NUMBERED 367,000 AND WAS GROWING AT A RAPID RATE. THIS GROWTH IS NOT ONLY DUE TO THE AGING OF SOCIETY, BUT TO IN-MIGRATION AS SOUTH CAROLINA IS THE EIGHTH FASTEST GROWING RETIREMENT STATE IN THE UNION. THE STATE'S CLIMATE AND QUALITY OF LIFE DRAW THE RETIREMENT COMMUNITY.

THIS FACT, IN ITSELF, CAN CAUSE PROBLEMS AS THE ELDERLY MOVE INTO SOUTH CAROLINA WITHOUT THE CORRESPONDING FAMILY NETWORK, AND AS THEY GROW OLDER AND THAT AGE CAUSES SICKNESS; THE ELDERLY THEN BEGIN TO REQUIRE SOME FORM OF LONG TERM CARE. CURRENTLY, THERE ARE OVER 12,000 NURSING HOME BEDS IN SOUTH CAROLINA WITH THE STATE'S MEDICAID PROGRAM FUNDING OVER 75%. THE REMAINING 25% OF THE 12,000 ARE FUNDED THROUGH PRIVATE PAY, MEDICARE AND OTHER CHARITABLE ORGANIZATIONS. IN ADDITION, AS I MENTIONED IN DESCRIBING THE LONG TERM CARE COUNCIL, HOME AND COMMUNITY BASED SERVICES ARE PROVIDED PRIMARILY THROUGH THE COMMUNITY LONG TERM CARE PROGRAM TO OVER 6,000 CLIENTS ANNUALLY. HOWEVER, THIS IS A WAIVERED PROGRAM AND IT IS LIMITED BY HCFA.

MR. CHAIRMAN, IF THE STATE FOLLOWS NATIONAL TRENDS, THEN ONE OF EVERY THREE INDIVIDUALS ARE RECEIVING THE SERVICES THEY NEED. IN OTHER WORDS, IT IS ESTIMATED THAT AN ADDITIONAL 80% OF ELIGIBLE DISABLED INDIVIDUALS RECEIVE INFORMAL CARE FROM FAMILIES, OTHER RELATIVES AND FRIENDS.

MR. CHAIRMAN, THE SITUATION IN SOUTH CAROLINA, WHILE NOT UNMANAGEABLE, COULD ONLY WORSEN - ESPECIALLY WITH AN INCREASING POPULATION OF ELDERLY INDIVIDUALS. AS POLICYMAKERS, THE LONG TERM CARE COUNCIL STANDS READY TO ADDRESS THE LONG-TERM CARE CONTINUUM ON THE LOCAL AND STATE LEVEL WHILE WE NOW TURN TO THE FEDERAL LEVEL FOR ASSISTANCE IN DESIGNING AN APPROPRIATE BENEFIT THAT COMPLEMENTS STATE RESOURCES TO ADDRESS THE ISSUE OF LONG TERM CARE.

THE LONG TERM CARE COUNCIL ANALYZED THE PROPOSED LEGISLATION FROM THE 100TH SESSION OF CONGRESS ALONG THE LINES OF THE NATIONAL ASSOCIATION OF STATE UNITS ON AGING. AGAIN, DUE TO TIME CONSTRAINTS, I WILL BE VERY BRIEF IN TERMS OF THE RECOMMENDATIONS. I WOULD DIRECT YOU, AGAIN, TO THE WRITTEN TESTIMONY, SUBMITTED AS AN APPENDIX FOR FURTHER DETAIL.

MR. CHAIRMAN, THE LONG TERM CARE COUNCIL RECOMMENDS THAT WITHIN A LONG-TERM CARE BENEFIT, THE **PROGRAM PARTICIPANTS** SHOULD INCLUDE COVERAGE OF THE ELDERLY 65 AND OVER POPULATION AND ADDITIONALLY THE DISABLED ADULT, AGE EIGHTEEN AND OVER POPULATION. THE COUNCIL RECOGNIZES THE NEEDS OF A DISABLED CHILD ARE OF SUPREME IMPORTANCE, BUT SUGGESTS THAT THESE NEEDS BE ADDRESSED IN SEPARATE LEGISLATION. THE IMMENSE PROGRAM DESIGN, AS FORESHADOWED BY THE MEDICARE CATASTROPHIC PROGRAM, WAS THE BASIS OF THIS RECOMMENDATION TO ONLY INCLUDE THE ELDERLY, 65 AND OVER POPULATION.

WHEN **DETERMINING BENEFITS**, THE LONG TERM CARE COUNCIL RECOMMENDS THAT LONG-TERM CARE SERVICES BE PROVIDED TO ALL WHO NEED THEM, REGARDLESS OF INCOME AND ADDRESSING THE PROGRAM PARTICIPANTS. ELIGIBILITY SHOULD BE BASED ON FUNCTIONAL, COGNITIVE, OR BEHAVIORAL LIMITATIONS, OR THE NEED FOR SUPERVISION BECAUSE OF THE RISK TO SAFETY OR HEALTH, OR THE NEED FOR SUPPORT OR TRAINING. IN ADDITION, ELIGIBILITY SHOULD DEPEND UPON THE INABILITY TO PERFORM 2 ACTIVITIES OF DAILY LIVING SKILLS THEREBY RESULTING IN HOME AND COMMUNITY BASED SERVICES. THE LONG TERM CARE COUNCIL BELIEVES THAT CONSIDERATION

NEEDS TO BE GIVEN TO THE CONCEPT OF INSTRUMENTAL ACTIVITY OF DAILY LIVING SKILLS. THESE COMPRISE THE ABILITY OF AN INDIVIDUAL TO CARRY OUT OTHER FUNCTIONAL DEFICITS THAN ADL SKILLS BUT ARE NEVERTHELESS IMPORTANT TO THE MAINTENANCE OF A INDIVIDUAL IN THE HOME OR COMMUNITY.

FURTHER MR. CHAIRMAN, THE LONG TERM CARE COUNCIL RECOMMENDS THAT A BENEFIT DETERMINATION SCHEME ENCOMPASS A COMPREHENSIVE ASSESSMENT MECHANISM THAT EQUATES RESULTS OF THE ASSESSMENT WITH APPROPRIATE SERVICES.

A SPECIFIC CATEGORY OF SERVICES RECEIVED ATTENTION DURING LONG TERM CARE COUNCIL DISCUSSION; MR. CHAIRMAN - THAT IS RESPITE CARE. THE COUNCIL RECOMMENDS AN EXPANSION OF THE BENEFIT EMPHASIZING THE NEED FOR COORDINATION IN THE FORMAL DELIVERY OF RESPITE CARE WHICH IS CURRENTLY DELIVERED IN A FRAGMENTED FASHION. THE COUNCIL ALSO SUGGESTS THAT THE INFORMAL FAMILY NETWORK AND CARE PROVIDED BY FRIENDS AND RELATIVES BE MAINTAINED TO COMPLEMENT A FORMAL RESPITE CARE BENEFIT.

IN REGARD TO NURSING HOME ELIGIBILITY, THE LONG TERM CARE COUNCIL RECOMMENDS MORE RESTRICTIVE NURSING HOME REQUIREMENTS THAN THE TWO ADL OR IADL STANDARDS. THIS PARTICULAR ELIGIBILITY CRITERIA SHOULD BE BASED ON CURRENT MEDICAID ELIGIBILITY RULES (STATE

SPECIFIC) IN ORDER TO BECOME ELIGIBLE FOR THE NEW LONG-TERM CARE BENEFIT. THE LONG TERM CARE COUNCIL SUPPORTS THE GENERAL INTENT WITHIN PREVIOUS FEDERAL INITIATIVES TO REDIRECT THE BIAS IN THE DELIVERY OF LONG-TERM CARE SERVICES FROM AN INSTITUTIONAL ARENA TO THE HOME AND COMMUNITY BASED ARENA.

MR. CHAIRMAN, THE LONG TERM CARE COUNCIL RECOMMENDS FOR ANY **BENEFIT PACKAGE** INCLUDED WITHIN A LONG-TERM CARE PROPOSAL, A COMPREHENSIVE RANGE OF FACILITY-BASED AND HOME AND COMMUNITY BASED HEALTH, SOCIAL AND SUPPORT SERVICES BE PROVIDED. IN ADDITION, FLEXIBILITY IN THE ADMINISTRATION BY THE INDIVIDUAL STATES IS TO MAINTAINED WITH THE BENEFIT PACKAGES, THEMSELVES, BASED UPON THE NEEDS OF THE INDIVIDUAL. WITHOUT DETAILING SPECIFIC SERVICES, THE COUNCIL WOULD RECOMMEND THAT ANY LONG-TERM CARE PACKAGE INCLUDE THE PROVISION OF SERVICES THAT ASSIST CLIENTS SERVED TO PERFORM ADLS, MAINTAIN INTEGRATION AND FAMILY SUPPORTS, ENHANCE INDEPENDENCE AND PREVENT INAPPROPRIATE INSTITUTIONALIZATION.

IN REGARD TO **PROGRAM ADMINISTRATION**, THE LONG TERM CARE COUNCIL SUGGESTS FLEXIBLE ADMINISTRATION OF BENEFITS BASED ON THE STATE LEVEL. THE FEDERAL GOVERNMENT SHOULD PROVIDE LEEWAY IN SETTING THE STANDARDS IN ORDER TO ENCOURAGE INNOVATION AMONG THE STATES.

MR. CHAIRMAN, AN INTEGRAL COMPONENT OF ADMINISTRATION OF BENEFITS IS CASE MANAGEMENT OR WHAT IS SOMETIMES REFERRED TO AS CARE COORDINATION. AS SEEN BY THE COUNCIL, CARE COORDINATION WOULD BE PROVIDED AS A SERVICE WITHIN A BENEFIT PACKAGE AND ALSO UTILIZED AS A MECHANISM FOR EFFECTIVE ADMINISTRATION TO ASSURE THE PROVISION OF APPROPRIATE SERVICES TO ALL PARTICIPANTS. ASSESSMENTS AND ELIGIBILITY DETERMINATIONS ARE TO BE COMPLETED BY A NON-SERVICE AGENCY AND ACTUAL SERVICES PROVIDED BY A SEPARATE ENTITY. AT THE TIME OF THE INITIAL ASSESSMENT, THE SEVERITY AND INTENSITY OF CARE COORDINATION SHOULD BE DETERMINED WITH THE IDEA IN MIND THAT CARE COORDINATION MAY BE PROVIDED AS AN OPTIONAL SERVICE IF REQUESTED AND CONTINGENT UPON THE BENEFICIARIES' SEVERITY OF ILLNESS OR DISABILITY.

MR. CHAIRMAN, THE STATE OF SOUTH CAROLINA STANDS FIRMLY BEHIND THIS IDEA OF STATE FLEXIBILITY AND STATE ADMINISTRATION OF THE PROGRAM DESIGNS.

ANOTHER ELEMENT OF THE ISSUE OF LONG TERM CARE AND A BENEFIT PACKAGE ARE **QUALITY ASSURANCES**. THE COUNCIL RECOMMENDS THAT A LONG-TERM CARE PACKAGE ENSURE HIGH QUALITY AND ACCESS TO ALL BY INCLUSION OF ADEQUATE CERTIFICATION STANDARDS FOR PROFESSIONAL AND ALL WORKERS INVOLVED IN THE DELIVERY OF SERVICES TO THE ELDERLY, WHETHER IN AN INSTITUTION, OR IN THE HOME OR COMMUNITY. COUNCIL WOULD ALSO RECOMMEND THE ESTABLISHMENT OF COMMUNITY ADVISORY BOARDS TO ACT IN ADVISORY STATUS TO THE STATE AGENCIES ADMINISTERING THE LONG-TERM CARE PROGRAM.

FINALLY, UNDER QUALITY ASSURANCES, MR. CHAIRMAN, THE COUNCIL WOULD RECOMMEND AN OUTCOME ORIENTED SYSTEM BASED ON WRITTEN PLANS OF CARE WHICH ARE A MAINSTAY OF CARE DELIVERY SYSTEMS THROUGHOUT THE UNITED STATES.

MR. CHAIRMAN, PERHAPS ONE OF THE MOST CONTROVERSIAL ELEMENTS OF THIS ISSUE IS THE FINANCING OF LONG TERM CARE. THE COUNCIL RECOGNIZES THAT IN LIGHT OF THE BUDGET DEFICIT, NEW SOURCES OF REVENUE WILL BE NEEDED. SPECIFICALLY, THE COUNCIL RECOMMENDS THE ELIMINATION OF THE CAP ON INCOME EXPOSED TO THE 1.45% MEDICARE PAYROLL TAX AND THE IMPLEMENTATION OF ESTATE AND GIFT TAXES WITH AN EXEMPTION ON ESTATES WHEN TRANSFERRED TO SPOUSES. REALIZING ADDITIONAL REVENUE ENHANCEMENTS WILL BE REQUIRED, THE COUNCIL IS AMENABLE TO THE USE OF EXCISE TAXES, LUXURY TAXES, INCREASES TO THE MEDICARE PART B PREMIUM, OR A SURTAX SIMILAR TO THE CONTROVERSIAL SURTAX WHICH IS NOW BEING UTILIZED TO FINANCE THE CATASTROPHIC PROGRAM.

A FINAL RECOMMENDATION FROM THE COUNCIL IN REGARD TO FINANCING - THE COUNCIL BELIEVES THAT THE SOCIAL SERVICE BLOCK GRANT PROGRAM AND TITLE III FROM THE OLDER AMERICANS ACT SHOULD REMAIN IN PLACE AS SUPPLEMENTS TO ANY LONG-TERM CARE PROPOSAL.

MR. CHAIRMAN, TO ASSIST IN THE CONTROL OF COSTS, THE COUNCIL RECOMMENDS THAT BENEFICIARIES ALSO ASSIST IN THE FINANCING OF ANY LONG-TERM CARE PROPOSALS - SPECIFICALLY, THE BENEFICIARY SHOULD BE RESPONSIBLE FOR COPAYMENTS AND DEDUCTIBLES. THESE COPAYMENTS AND DEDUCTIBLES SHOULD BE BASED ON A SLIDING FEE SCALE TO GAUGE FOR THE BENEFICIARIES ABILITY TO PAY. IT IS RECOMMENDED THAT THE FEE SCALES BE WRITTEN ON THE FEDERAL LEVEL TO SET UNIFORM STANDARDS WITH STATE AND REGIONAL DIFFERENCES CALCULATED AND UTILIZED AS THE PROGRAM PROCEEDS. THE COPAYMENTS AND DEDUCTIBLES ARE INTENDED TO CONTROL UTILIZATION AS WELL AS ASSIST IN DEFINING A ROLE FOR PRIVATE LONG-TERM CARE INSURANCE. IN ADDITION, THE LONG-TERM CARE COUNCIL WOULD RECOMMEND COVERAGE OF COMMUNITY SERVICES AND REIMBURSEMENT TO BE CAPPED AT EQUAL TO BUT NOT MORE THAN THE COST OF CARE IN A SKILLED NURSING FACILITY IN ORDER TO CONTAIN COSTS.

MR. CHAIRMAN, OUR FINAL RECOMMENDATIONS HAVE TO DO WITH TWO BROAD AREAS THAT PERVADE THE ENTIRE ISSUE OF LONG-TERM CARE - THAT OF PRIVATE LONG-TERM CARE INSURANCE AND THE APPROPRIATE ROLE OF MEDICAID. THE LONG TERM CARE COUNCIL WOULD RECOMMEND MORE RESEARCH ON THE EFFICACY OF THE PRIVATE LONG-TERM CARE MARKET TO REDUCE PUBLIC COSTS WHILE THE MARKET ITSELF MATURES. THIS IN LIGHT OF THE ROLE THAT PRIVATE LONG-TERM CARE INSURANCE COULD PLAY.

IN ADDITION, MR. CHAIRMAN, MEDICAID PLAYS A MOST INVOLVED ROLE IN THE FINANCING OF LONG-TERM CARE IN SOUTH CAROLINA AS WELL AS ACROSS THIS NATION. THE LONG-TERM CARE COUNCIL REALIZES THAT A CERTAIN POPULATION WILL NEVER BE ABLE TO AFFORD LONG-TERM CARE INSURANCE OR EVEN TO ASSIST IN PROPOSED COPAYMENTS AND DEDUCTIBLES AND THUS THE COUNCIL WOULD SUPPORT THE GOAL OF PREVIOUS LEGISLATIVE INITIATIVES TO REDISTRIBUTE THE BURDEN FROM MEDICAID TO A SOCIAL INSURANCE PROGRAM. SPECIFICALLY, THE ROLE OF MEDICAID WOULD CONTINUE TO COVER THE DEDUCTIBLES, COINSURANCE AMOUNTS AND WAITING PERIODS FOR PARTICIPANTS BELOW THE POVERTY LEVEL.

IN FINAL ANALYSIS, THE APPROPRIATE LONG-TERM CARE PACKAGE SHOULD INCLUDE QUALITY SERVICES PROVIDED IN THE LEAST RESTRICTIVE ENVIRONMENT. HOME AND COMMUNITY BASED SERVICES, RESPITE CARE AND NURSING HOME CARE SHOULD ALL BE ADDRESSED IN ONE COMPREHENSIVE PROPOSAL WHICH PAYS PARTICULAR ATTENTION TO STATE ADMINISTRATION WITH FLEXIBILITY FOR SERVICE PROVISION, MANAGEMENT AND ELIGIBILITY. IN ADDITION, FUNDING RESOURCES SHOULD BE MERGED WITH CONTRIBUTIONS FROM MEDICARE, MEDICAID, AND FROM PRIVATE SOURCES.

THE SOUTH CAROLINA LONG-TERM CARE COUNCIL STANDS READY TO ADDRESS THIS ISSUE AND TO ASSIST YOU, THE MEMBERS OF THE PEPPER COMMISSION IN YOUR WORK NOT ONLY FOR LONG TERM CARE BUT ALSO IN PROVIDING COMPREHENSIVE CARE FOR THE ESTIMATED 37 MILLION UNINSURED.

WE HOPE THESE RECOMMENDATIONS FROM THE COUNCIL WILL ASSIST YOU IN OUTLINING NATIONAL POLICY DIRECTIVES. WE REALIZE THE HETEROGENEOUS ASPECTS OF THE U.S. AND EACH STATES' VARYING APPROACHES IN PROVIDING AND FINANCING LONG-TERM CARE. HOWEVER, COMMONALTIES DO EXIST AND THEY REFLECT THE WEALTH OF EXPERIENCE EACH STATE HAS GAINED IN DEALING WITH LONG TERM CARE.

MR. CHAIRMAN, I THANK YOU FOR THIS OPPORTUNITY TO SPEAK WITH YOU TODAY AND TO SUBMIT TESTIMONY - THE SOUTH CAROLINA LONG TERM CARE COUNCIL LOOKS FORWARD TO WORKING WITH THE US BIPARTISAN COMMISSION FOR A VIABLE SOLUTION.

TESTIMONY OF THE SOUTH CAROLINA LONG-TERM CARE COUNCIL

PROVIDED TO THE U.S. BIPARTISAN COMMISSION
ON COMPREHENSIVE HEALTH CARE

LEGISLATIVE INITIATIVES

AND

POLICY DIRECTIONS

RECOMMENDATIONS

OCTOBER 9, 1989

THE SOUTH CAROLINA LONG-TERM CARE COUNCIL'S TESTIMONY TO THE U.S. BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE

"LEGISLATIVE INITIATIVES AND POLICY DIRECTIONS"

INTRODUCTION

Mr. Chairman, Distinguished Members of the U.S. Bipartisan Commission, Ladies and Gentlemen, it is an honor for me to be here today to speak with you on a issue that is certainly one of the most significant concerns this country is facing today. Long term care and the need for long term care will affect all of us in some way; whether it is providing care for our parents or a disabled child, or as we, ourselves, grow older, and seek such services. We will all deal with the issue of growing older and or providing care for our loved ones.

Long-term care for the elderly and the disabled has fast seized the public agenda. The public's concern has risen over the question of the appropriate provision of services and concern over how to finance that care has risen proportionately. One of the earliest indicators of continuing debate and resulting action appeared within the dialogue of the Medicare Catastrophic Comprehensive Coverage Act of 1988. During the course of those legislative discussions, the point was emotionally and yet pointedly advanced that true "catastrophic" results were most apparent when providing and seeking to provide long-term care.

The call for action on long-term care continues. Interest groups, such as the National Society to Preserve Social Security and Medicare, (NSPSSM) have lobbied vociferously for the formulation and implementation of a comprehensive long-term care benefit. In the wake of this continued debate and before the ink was dry on the Catastrophic Coverage Act, critics and elderly interest groups, epitomized by the NSPSSM, were calling for its repeal arguing that the Act did not address the uncovered liability many elderly face for long-term care costs; that the financing mechanisms were unfair; and insisting that benefits did not equal costs of the program funded totally by the beneficiaries. Proponents of Catastrophic, namely the American Association of Retired Persons, and key sponsors of the legislation in Congress, have maintained that the Act was and still is warranted, and it provides the necessary benefits which are commensurate with costs of the program.

Mr. Chairman, The Long Term Care Council of South Carolina has answered this call from interest groups as well as from Congress. The Long Term Care Council was formulated in 1978 for the purpose of developing a statewide long term care management system which incorporated pre-admission assessment, case management service and continued oversight of the system. This project became known as the Community Long Term Care Project and is today very successful and a highly popular alternative to nursing home institutionalization in South Carolina. In 1984, the Council's role was expanded into other areas of long term care and in 1987, the South Carolina General Assembly approved a measure making the Long Term Care Council an official state entity with the charge to identify future policy issues in long term care, conduct research and demonstration activities related to those issues and to develop recommendations for a statewide service delivery system for all health impaired persons in South Carolina. The Council is made up of twelve members including the Governor, the Executive Director of the State Health and Human Services Finance Commission and the Commission on Aging, the Commissioners from The Department of Mental Health, The Department of Health and Environmental Control, The Department of Social Services, and the Department of Mental Retardation, with representatives of the South Carolina General Assembly and three gubernatorial appointees.

In November 1988, Council appointed a task force to analyze legislation introduced from the 100th Congress and to survey for program, policy and budgetary impact. As a reaction to the five major initiatives in Congress at that time, The Long Term Care Council formulated recommendations which are here today provided for The U.S. Bipartisan Commission on Comprehensive Health Care.

And thus, Mr. Chairman, The South Carolina Long Term Care Council is reflective of those agencies in the state which deliver and finance long term care and as a group are in the most advantageous position to offer the U.S. Bipartisan Commission a coherent picture of the needs of the long term care delivery system in South Carolina and the resulting desired policy directions in which the Council is suggesting today. What follows are the basic tenets the Council considered along with the complete recommendations for any comprehensive long term care initiative considered by Congress.

DEFINITIONS AND DEMOGRAPHICS

Several definitions of long-term care have advanced and some commonalties have emerged. To that end, Council defines long-term care as those services provided over a long period of time to persons with chronic illnesses and disabilities who need assistance with regular, everyday activities, such as eating, bathing, and getting dressed. These services can be provided at home, in the community, or in an institution. Restated, long-term care refers to an array of medical, social, and supportive services for individuals in nursing homes or in the community who, for an extended period of time, are dependent on others for physical assistance.

With this definition, the Council turned to the overall picture to reveal current demand for long-term care as well as future demand. These statistics foreshadow the impending problem facing the United States in the area of long-term care as the nation's elderly population grows at a phenomenal rate.

Mr. Chairman, in 1988, the elderly's out-of-pocket health care costs totaled some $73 billion; overall, the elderly spent $175 billion on health care in 1988. Many sources fund this health care including Medicare, Medicaid, current and former employers and of course, the elderly population themselves. More specifically, Mr. Chairman, the General Accounting Office recently issued a report detailing perspectives of long-term care - specifically, those of need, access and cost. This report illustrated the picture of long-term care in the U.S. in 1985. At that time, an estimated 6.2 to 6.5 million persons were dependent on others for care with over one-fifth (1.3 million) residing in nursing homes. It is estimated that in 1989, some 7.1 million elderly Americans are disabled and need some form of long-term care. The general theory is that for every elderly person in a nursing home, there is at least twice as many persons living in the community who need care and of that group, two-thirds say they do not get the care they need. Of the entire group of the elderly who receive long-term care, over 80% live in the community and rely on informal care. Projections for the year 2020 estimate that the total number of dependent elderly individuals could increase and exceed 14 million.

The General Accounting Office report also detailed that over $45 billion was expended nationally in 1985 for long-term care, from both public (52%) and private (48%) sources. Nursing home care accounted for just over $36 billion (80%) of the $45 billion total long-term care expenditure with the remaining $9 billion (20%) spent on home and community based care. Medicaid is by far the major public financing mechanism for nursing home care and accounted for, in 1985, $17 billion or 90% of the total of publicly funded nursing home care with the remaining 10% funded through other public programs.

The remaining $9 billion of total home and community based care expenditures were evenly split between public and private sources. (Medicare accounted for $2.3 billion of the total publicly spent on home health care; $4.5 billion.) Out-of-pocket costs represent the private spending facet of long-term care with payments accounting for $16 billion of privately paid nursing home care and $4.6 billion for home and community based care.

Overall, the distribution of long-term care expenditures reflects that Medicaid covers 41% of all long-term care; Medicare funds 7%; out-of-pocket expenses finance 44% of all long-term care with 8% of all long-term care funded by other public and private sources.

Mr. Chairman, the elderly 65 and over population in South Carolina was estimated to be over 367,000 in 1987 rising from a total of 287,000 as recorded by the 1980 U.S. Census. Currently, there are over 12,000 nursing home beds in South Carolina with the State's Medicaid program funding some 75% of the total number of beds. The remaining 25% of the 12,000 beds are funded through private pay, Medicare and charitable organizations. In addition, long-term care is provided in South Carolina through the Community Long-term Care Program which provides home and community based services to some 6,000 disabled individuals annually. If the state follows national trends, then one out of every three individuals are receiving the services they need. In other words, it is estimated that an additional 80% of eligible disabled individuals receive informal care from families, other relatives and friends.

Outside forces are now requiring South Carolina and her policymakers to address the long-term care issue more thoroughly. These include such forces as: a) the Medicare Catastrophic Coverage Act which added new dual eligibles to the states' Medicaid rolls; b) an increased elderly population - South Carolina is the eighth fastest growing retirement state in the nation taking into account in-migration and out-migration; and c) federal legislative initiatives seeking to change the delivery and financing of long-term care. Thus, there is a need to be proactive in this particular policy arena and the South Carolina Long Term Care Council is leading the charge.

The Long Term Care Council now offers recommendations on many of the aspects of long-term care legislation most recently discussed on Capitol Hill. These proposals represent a thorough analysis of the South Carolina perspective; the realizations of what can be accomplished; the political atmosphere of Congress; and the perceived need of long-term care in South Carolina.

PROGRAM PARTICIPANTS

One of the larger questions involved in proposing comprehensive long-term care initiatives is just who should be covered? Specifically, any comprehensive legislative initiative should cover the elderly 65 and over population plus the adult eighteen and over disabled population. Discussions surfaced within Council on the possibility of covering a larger population; one that included disabled children. The Long Term Care Council recognizes that this population is in need of long term care services, however, the Council could not determine a feasible scheme for eligibility determination within our proposal. In addition, there is currently separate federal legislation expanding Medicaid to cover this population for community habilitation services. The Council suggests supports separate legislative action.

BENEFIT DETERMINATION

Overall, the Long Term Care Council recommends adoption of a broad statement recognizing that long-term care services should be available to all who need them, regardless of income and addressing the program participants suggested above. Eligibility should be based on functional, cognitive or behavioral limitations, or the need for supervision because of the risk to safety or health, or the need for support or training.

Within this broad framework, the Council specifically recommends that a proposed long-term care package include the basic premise that the inability to perform 2 ADLs (Activities of Daily Living - bathing, dressing, toileting, continence, transferring, mobility, and eating) should result in eligibility for home and community based services. The Council recognizes that this recommendation within current operative program guidelines represents an expansion of eligibility to larger categories of potential eligible individuals in South Carolina.

The Long Term Care Council also identified and discussed the concept of IADLs or Instrumental Activities of Daily Living and spoke to their appropriate role within a comprehensive package. IADLs comprise the ability of an individual to carry out household and mobility activities such as preparing meals, doing laundry, performing heavy work or light housework and getting around outside. This IADL level of capability, again, would increase the pool of potential eligibles for the long-term care benefit. The Council believes that consideration should be given to IADL inclusion within long-term care proposals to address the need for support in this area.

In addition, the Council believes that a benefit determination methodology must encompass a comprehensive assessment mechanism that would equate the results of that assessment with appropriate benefit package. Often times, eligibility criteria for health benefits have little to do with the social service needs of an impaired elderly individual and may result in the limitation of access to services. For example, if a beneficiary is unable to perform the ADL of eating, then it is also more likely that the same individual in unable to perform IADL activities such as shopping, cooking or the preparation of food. The intent here, is to match services within a benefit package or within a care plan that adequately addresses an individual's needs. Thus, the conclusion can be drawn that upon completion of a comprehensive assessment; if that individual cannot perform an ADL and crucial IADLs, then eligibility and services should be thoroughly matched with the benefit package.

A second level of eligibility criteria is also suggested. The Council recommends that more restrictive nursing home eligibility requirements be based on current Medicaid criteria thereby containing costs and limiting the number of individuals entering nursing institutions. A basic intent of previous federal initiatives has been to redirect resources from the institutional arena and offer home and community based services on a wider scale. The Council supports this move.

BENEFIT PACKAGE

The Council recommends that a national long-term care program should provide a comprehensive range of facility-based and home-community based health, social and support services. These services should be provided in such a way as to maintain and enhance personal independence in the community and in the setting preferred by the beneficiary and family. This range of services would include an expansion of respite care as a benefit.

In addition, states should maintain flexibility in the administration of the benefit packages, which should be based upon the needs of the individual. Services which are necessary to assist a client to perform ADLs; maintain social integration and family support, enhance independence and prevent inappropriate institutionalization should be included in a long-term care benefit package. This recommendation supports the Council's previous discussion of disability tests matching benefit packages.

PROGRAM ADMINISTRATION

The Long Term Care Council recommends that the administration of any proposed long-term care benefit program be based on the state level. In keeping with earlier recommendations, flexibility is the key phrase and states must be encouraged to be innovative and flexible in administering and delivering long-term care services. The Federal government must also provide enough leeway in setting those standards in order to encourage this innovative mode within the states.

Case management or care coordination, as seen by the Long Term Care Council, would be provided as a service within a benefit package and also utilized as a mechanism for effective administration to assure the provision of appropriate services to all participants. First, assessments and eligibility determinations should be completed by a non-service agency and actual services provided by a separate entity. Furthermore, and at the time of the initial comprehensive assessment, the severity and intensity of care coordination should be determined with the idea in mind that care coordination may be provided as an optional service if requested and contingent upon the beneficiary's severity of illness or disability.

The role of the states in the current delivery of long-term care services is well documented. States have accomplished major strides in the administration of long-term care services specifically in the area of utilization control. In addition, some states have spent considerable resources to augment Federal/State programs to support home and community based programs. This past involvement places the states in a unique position for administration of a long-term care program.

QUALITY ASSURANCES

Overall, the Long Term Care Council recommends that a long-term care program ensure high quality and access to care for all. Specific recommendations include adequate certification standards for professionals and other workers involved in the delivery of services to the elderly, whether in an institution, the community or at home. The Council would also recommend the establishment of Community Advisory Committees to act in advisory status to the state agencies administering the long-term care program. In addition, a quality assurance system should be outcome oriented and based on written plans of care.

FINANCING

Perhaps one of most controversial and hotly debated issues addressed during Congressional discussions will be the issue of financing the long term care benefit. In light of the recent Medicare Catastrophic Act and its financing provisions placed on program beneficiaries, the question of who will pay for expansions under any new benefit program is not readily answered. The Council recognizes new resources must be tapped in order to fund these recommendations as well as the specific program provisions which will be proposed in Congress.

The resources recommended to be tapped include:

1) The elimination of the cap on income exposed to the 1.45% Medicare payroll tax based on estimates that nearly 95% of all Americans contribute 1.45% of their entire income to Medicare. This change would affect that 5% who make over $48,000 annually and who do not contribute on any of their income above $48,000;

2) The implementation of estate and gift taxes with an exemption of estates when transferred to a spouse.

Other forms of public financing may be necessary and the Long Term Care Council supports excise taxes, luxury taxes, increases in the Medicare Part B premium, or a surtax similar to the one included in the Catastrophic Act in order to finance the long-term care benefit, which is expected to cost billions.

The Council would also recommend that the Social Services Block Grant program and Title III funds for the Older Americans Act remain in place as supplements to any program proposal.

DEDUCTIBLES / COST SHARING / COST CONTROLS

In order to assist in the financing of a long-term care package, the South Carolina Long Term Care Council recommends some form of responsibility placed on the beneficiaries. Specifically, the Council recommends the beneficiary be responsible for deductibles and copayments. These copayments and deductibles should be based on a sliding scale to gauge for ability to pay. Fee scales should be written on the Federal level to set uniform standards with State and Regional differences calculated and utilized as the program progresses. In addition, suggested deductibles and copayments are intended to control utilization and limit Federal expenditures and subsequently define a role for the application of private long-term care insurance. The use of fee schedules or any other perspectively set reimbursement mechanisms should be a fundamental element of cost controls.

The Council also suggests a specific recommendation in regard to community services and reimbursement; coverage of such services should be capped at equal to but not more than the cost of skilled care in a nursing facility in order to contain costs.

BROAD AREAS OF DISCUSSION

The Long Term Care Council also has recognized broader issues within long-term care which affect elements of the entire issue. One such element is private long-term care insurance. The infancy of the market has caused skepticism among policymakers about the products offered; the quality, affordability, and range of benefits. It is true that unregulated, the private long-term care market has offered less than full benefits at a sizable cost to beneficiaries. However, states such as South Carolina, have taken a lead in regulating this industry requiring that policies marketed within their borders adhere to strict standards addressing loss/ratios, prior hospitalization requirements, and inflation protections. The Council recognizes the role that private long-term care insurance could play and recommends more research on the efficacy of the private long-term care industry to reduce public costs while the market continues to perfect long-term care policies. This research should be directed toward better coverage of home and community based services difficult for the insurance industry to gauge because eligibility is confined to a limited number of persons.

A second broad concern surrounds the appropriate role of Medicaid in the financing of long-term care and the question of continued financing of long-term care for the poor. The Long Term Care Council believes that there will always be a certain population too impoverished to afford long-term care insurance or even to assist in copayments and deductibles. In addition, the Medicaid program has become so institutionalized within the long-term care spectrum that total removal from the field will most likely not occur. Recent initiatives have as a lofty goal - the redistribution of the burden from Medicaid sponsorship to a social insurance program and private sources. The Council supports this goal and recommends for Medicaid, a role for participation in a long-term care program whereby the program covers deductibles, coinsurance and waiting periods for participants below the poverty level.

CONCLUSIONS

In final analysis, the appropriate long-term care package should include quality services provided in the least restrictive environment. Home and community based services, respite care and nursing home care should all be addressed under one comprehensive proposal which pays particular attention to state administration with flexibility of service provision, management and eligibility. In addition, funding resources should be merged with appropriate contributions from Medicare, Medicaid and from private sources.

The South Carolina Long Term Care Council stands ready to address this issue and to assist the members of the U.S. Bipartisan Commission in your work on not only long term care but that of comprehensive care to the 37 million uninsured Americans.

The Council would hope these recommendations from South Carolina will assist you in outlining policy directives. We realize the heterogeneous aspects of the U.S. and each states' varying approaches in providing and financing long term care. However, commonalties do exist and they reflect the wealth of experience each state has gained in dealing with long term care.

I thank you for the honor and opportunity to speak with you today and the South Carolina Long Term Care Council looks forward to working with the U.S. Bipartisan Commission toward a viable solution.

BIBLIOGRAPHICAL SOURCES

1) Long-Term Care For The Elderly; Issues of Need, Access and Cost. A GAO Report, November 1988. As Provided For: The Chairman, Subcommittee on Health and Long-Term Care, Select Committee on Aging, House of Representatives.

2) Health Care Costs For America's Elderly, 1977-88. A Report by the Chairman of the Select Committee on Aging, U.S. House of Representatives. March 1989; U.S. Goverment Printing Office.

3) Federal Long-Term Care Reform: A Proposal by the National Association of State Units of Aging. Published June 10, 1988 and Adopted by the Membership.

4) Long-Term Care For the Elderly, A Congressional Research Service Issue Brief. Authored By: Richard J. Price and Carol O'Shaughnessy. Updated February 1989.

MEMBER AGENCIES

The Joint Legislative Committee on Aging
The Department of Health and Environmental Control
The State Health and Human Services Finance Commission
The Department of Mental Health
Office of the Governor - Health and Human Services
The Department of Mental Retardation
The Department of Social Services
The Joint Health Care Planning and Oversight Committee
The South Carolina Commission on Aging

THE SOUTH CAROLINA LONG TERM CARE COUNCIL

OCTOBER 9, 1989

BACKGROUND

The South Carolina Long Term Care Council was formulated in 1978 for the purpose of developing a statewide long term care management system which incorporated pre-admission assessment, case management services and continued oversight of that system. This project became known as the Community Long Term Care Project and is today a very successful and highly popular alternative to nursing home institutionalization in South Carolina. In 1984, the Council's role was expanded into other areas of long term care and in 1987, the South Carolina General Assembly approved a measure making the Long Term Care Council an official state entity with the charge to identify future policy issues in long term care, conduct research and demonstration activities related to those issues and to develop recommendations for a statewide service delivery system for all health impaired persons in South Carolina.

The Council consists of twelve members including the Governor, the Executive Director of the State Health and Human Services Finance Commission, and the Commission on Aging, the Commissioners from the The Department of Mental Health, The Department of Health and Environmental Control, The Department of Social Services, and The Department of Mental Retardation, with representatives of the South Carolina General Assembly and three gubernatorial appointees.

In November of 1988, Council appointed a task force to analyze legislation introduced during the 100th Congressional Session and to survey for potential program, policy, and fiscal impact. As a reaction to the five major initiatives in Congress at that time, The Long Term Care Council formulated recommendations which are here today provided for The U.S. Bipartisan Commission on Comprehensive Health Care.

The following is a short synopsis of approved positions on program participants, benefit determinations, benefit packages, program administration, quality assurances, financing, deductibles - cost sharing - cost controls, and a statement on broad areas of discussion addressing the Medicaid program and the private long term care insurance market.

LONG TERM CARE COUNCIL RECOMMENDATIONS / A RECAPITULATION

PROGRAM PARTICIPANTS

1) The Long Term Care Council recommends coverage, within any proposed long-term care package, of the elderly 65 and over population and additionally the disabled adult, eighteen over population. The Committee recognizes the needs of the disabled child population however delays addressing this population while Federal initiatives, which enjoy wide bipartisan support and reform Medicaid, are being debated in Congress. Thus, long-term care for the child population should be addressed separately by the Long-Term Care Council.

BENEFIT DETERMINATION

1) Council recommends that long-term care be provided to all who need them, regardless of income and address the program participants listed above.

2) Eligibility should be based on functional, cognitive, or behavioral limitations, or the need for supervision because of the risk to safety or health, or the need for support or training.

3) Within a proposed long-term care package, eligibility should depend upon the inability to perform 2 Activity of Daily Living skills which wouuld result in eligibility for home and community based services.

4) Consideration needs to be given to Instrumental Activity of Daily Living skills when designing long-term care proposals. These skills include futher functional deficits not always addressed but nevertheless important to the maintenance of a individual in the home and community.

5) Council also recommends that a benefit determination scheme encompass a comprehensive assessment mechanism that equates results of the assessment with appropriate services.

6) The Council recommends an expansion of the respite care benefit emphasizing the need for coordination in the formal delivery of this service when it is basically now provided in a limited, fragmented fashion. Most disabled elderly depend on the family network or friends and this too should be maintained.

7) In regard to nursing home eligibility, the Long Term Care Council recommends more restrictive nursing home requirements by basing these on current Medicaid eligibility criteria.

8) The Council supports the general intent within previous Federal legislative initiatives to redirect the bias in the delivery of long-term care services from an institutional arena to the home and community based arena.

BENEFIT PACKAGE

1) Council recommends that any long-term care proposal provide a comprehensive range of facility-based and home and community based health, social, and support services.

2) Flexibility in the administration by the individual states is to maintained and with the packages themselves based upon the needs of the eligible individual.

3) Any long-term care package should include the provision of services that assist clients served to perform ADLs, maintain integration and family supports, enhance independence and prevent inappropriate institutionalization.

PROGRAM ADMINISTRATION

1) The Counicl recommends that the administration of any proposed long-term care program be based on the state level.

2) The Council recommends that uniform benefit levels should be established at the Federal level with state administration of those benefit levels.

3) The Federal Government should provide leeway in setting the standards in order to encourage innovation among the states.

4) The Long Term Care Council recommends that an appropriate state agency should administer the program based on a care coordination model recognizing that care coordination must be a central function of the agency while involving program administration and addressed on two levels. More specifically, a comprehensive assessment would be completed by a non-service agency and services services provided by a separate entity.

At the time of this initial assessment, the severity and intensity of needed care coordination will be determined with the idea in mind that care coordination will be provided upon request from the individual and contigent upon the individual's severity of illness.

QUALITY ASSURANCES

1) Council recommends that a long-term care comprehensive prpgram ensure high quality and access to all by inclusion of adequate certification standards for professionals involved in the delivery of services and for all workers providing services, whether in the home, the community or in an institution.

2) Recommendations also surround the establishment of Consumer Boards to act in advisory status to the state agencies administering the long-term care program.

3) A quality assurance system should be outcome oriented and based on written plans of care.

FINANCING

1) In light of the budget deficit, the Council recognizes that new sources of revenue for this ambitious program will need to be tapped. Specifically, the Council recommends the elimination of the cap on income exposed to the 1.45% Medicare payroll tax.

2) The Council additionally recommends the implementation of estate and gift taxes with an exemption on estates when transferred to a spouse.

3) Realizing other revenue enhancements may be needed, the Long Term Care Council is amenable to excise taxes, luxury taxes, increases in the Part B premium, or a surtax similar to the one included in the Medicare Catastrophic Coverage Act of 1988.

4) The Council recommends that the Social Service Block Grant program and Title III funds for the Older Americans Act remain in place as supplements to a long-term care proposal.

DEDUCTIBLES / COST SHARING / COST CONTROLS

1) The Long Term Care Council recommends that beneficiaries assist in the financing of any long-term care proposals. Specifically, a beneficiary should be responsible for copayments and deductibles.

2) In addition, the copayments and deductibles should be based on a sliding scale to gauge for beneficiary ability to pay.

3) The fee scales should be written on the Federal level to set uniform standards with State and Regional differences calculated and utilized as the program proceeds.

4) The copayments and deductibles are intended to control utilization as well assist in defining a role for private long-term care insurance.

5) The Council would also recommend in regard to community services and reimbursement; coverage of such services should be capped at equal to but not more than the cost of care in a skilled nursing facility in order to contain costs.

BROAD AREAS OF DISCUSSION

1) Private long-term care insurance is an emerging industry in its infancy and is the cause of some skepticism among policymakers. The Long Term Care Council realizes the role that private long-term care insurance could play and recommends more research on the efficacy of the private long-term care care market to reduce public costs while the market itself matures.

2) Medicaid plays a most involved role in the financing, delivery and administration of long-term care in South Carolina as well as the nation. Council believes that there will always be a certain population too impoverished to afford long-term care insurance or even to assist in copayments and deductibles. Realizing the above, Council supports the goal of previous legislative initiatives to redistribute the burden from Medicaid to a social insurance program. Specifically, the role of Medicaid would continue to cover deductibles, coinsurance amounts and waiting periods for participants below the poverty level.

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HEARING ON LONG-TERM CARE AND ACCESS TO CARE
October 4, 1989

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.

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Summary of Issues in National Multiple Sclerosis Society's Testimony on Long-Term Care Needs.

- Long term care for young and middle-aged adults with disabilities extends over many years and therefore may have greater impact than for elderly people.
- Often the only option available is a nursing home which is ill-equipped to deal with non-elderly residents.
- Nursing homes are inappropriate solutions for many who could live in their homes if they had a minimum of care.
- Young children must sometimes serve as the primary caregivers of young and middle-aged disabled parents. This can create an enormous burden on the child. There is also a psychological burden if the non-elderly parent enters a nursing home.
- Disabled adults may also become burdens for their parents, who may be at or nearing old age. Some elderly parents are incapable of providing the necessary care. Others sometimes become disabled themselves due to the strain.
- Even when home care is available, costly skilled care is sometimes unnecessarily mandated (e.g., to give simple medication).
- Long-term care should include varied living options (e.g., independent living centers, group homes, and accessible community housing).
- Long-term care insurance that excludes people with pre-existing conditions is not a solution.
- People with disabilities who become eligible for SSDI have a 24-month waiting period before Medicare coverage begins. This wait should be eliminated.
- 8 case histories included.

MR. CHAIRMAN, My name is Thor Hanson. I am a retired Navy Vice Admiral and the President and CEO of the National Multiple Sclerosis Society. I appreciate the opportunity to present to The Pepper Commission the issues facing the 250,000 Americans with multiple sclerosis, and the hundreds of thousands of family, friends and health care professionals in this country who must also deal with the effects of this disease each day.

Multiple sclerosis is a disease of the brain and spinal cord. Its first symptoms generally occur between ages 20 and 40. There is no known cure and its cause is unknown. Its course is typically marked by extreme variability and unpredictability, producing enormous coping problems for affected people and their families. Until the development of magnetic resonance imaging (MRI), a technological advance that produces detailed images of body tissues by using a magnetic field, the diagnosis of multiple sclerosis often took years of testing and produced untold emotional distress. Those experiencing symptoms were often labelled alcoholic or psychotic with no means of proving actual physical illness. Many were institutionalized in mental hospitals and lost jobs, families and friends.

Despite today's improved diagnostic methods, major problems remain. Over a lifetime of living with MS, which often amounts to thirty, forty or even fifty years, comprehensive long-term care is critical. But such care is usually unaffordable or unavailable.

An estimated 8-12,000 people with MS, many of whom are young, live in geriatric nursing homes where most or all other residents are in their 70s, 80s or 90s. Some are like the woman with MS in Little Rock who testified before this commission. She had to give up her home five years ago, at age 50, and move to a nursing home. This was because she lacked two hours of home care a day.

This commission must address two issues covered here. First, the lack of home and community services. Second, that due to the absence of such services, many young people who are disabled, whether with MS, spinal cord injury, or other conditions, must live for decades in institutional settings not prepared to meet their needs.

Because of a lack of home and community services, the nursing home is often the only option available to people with MS and their families. For example, lack of respite care can lead to family disintegration—the spouse, child, or elderly parent provides all the care without relief, until he or she breaks down. One in three hospitalizations of people with MS is a direct result of a family's unmet respite care need. The hospitalization is acute care at high cost to the family and the insurance carrier. Ultimately of course, society pays, with higher premiums and taxes to cover these unnecessarily inflated medical costs.

One problem creates another. Early entry of a young parent into a nursing home, or the strain on a child forced to care for a parent with MS, can cause school problems and emotional distress for such children, often requiring counseling. A woman in West Virginia with children 8 and 10 years old cried to us, "My children don't know what normal is!"

A different type of problem occurs at the other end of the age continuum. Since MS generally affects young adults, their mothers and fathers are often at or nearing old age. Aging parents frequently find themselves physically incapable of assisting their children with activities of daily living--bathing, shaving, brushing teeth, transferring from bed to a chair, dressing, and cooking. This help could be performed by minimally trained individuals, enabling those with MS to participate in the community and perhaps even to obtain employment. It would also relieve the aged parents of their caregiving difficulties. This type of coverage is often unavailable, however, or only available for brief periods.

Even when home care is available, home health aides are prohibited from administering medication or performing simple procedures, necessitating costly skilled nurses to provide this "care" at home. This wastes the time of skilled workers, and adds considerable expense.

Another need is for new living arrangements. Options should be varied to provide choices for particular situations. Independent living centers for the young disabled who are generally mentally alert is one priority. Group homes for the disabled who may need additional care is another option. Accessible community housing is also essential to bring the disabled into the mainstream of society.

As recognized by the Americans with Disabilities Act now being considered by the Senate, accessibility of public accommodations, transportation, private and public workplaces, schools, and other facilities is essential to allow maximum participation of people with disabilities.

In view of the range of these issues, we grow concerned when we hear that long-term care insurance is the solution being given great consideration. Such insurance is probably not a viable option. Those who need it most--people with pre-existing conditions like multiple sclerosis, diabetes, epilepsy and other life-long disabling diseases—are the most likely to be excluded from insurance coverage. They are now. Some insurance companies are requesting tax breaks in exchange for the development of long-term care policies. Yet experience suggests they would exclude pre-existing conditions to limit their risks.

Before presenting a few case histories representative of problems for non-elderly adult people with disabilities, I ask that the Commission focus on a specific Medicare issue, the waiting period for disabled individuals.*

Medicare eligibility based on disability is contingent on qualifying for Social Security Disability Insurance (SSDI). After that eligibility is established, a two-year waiting period is applied before Medicare eligibility is established. During that period, many disabled people obviously have inadequate health-care coverage.

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*The history of the legislation creating the Commission indicates that the Commission was expected to focus upon the Medicare waiting period. The legislative history is found in the report of the House Energy and Commerce Committee on the catastrophic health insurance legislation.

Finally, let me present some vignettes that express our concerns better than any testimony I can write. These are true stories of experiences to be found all across America. The problems continue and grow and I thus urge you to create bold solutions to the nation's long-term care problems.

- In Montana a woman with MS was cared for entirely by her husband for five years until he died of cancer. Left alone with three children, she is cared for by the 20-year old, who also tends his 13-year old sibling. The middle child, at 16, dropped out of school.

- In Jacksonville, Florida a 52 year old woman with MS is bed-bound, lives in diapers, and takes medication to avoid going to the bathroom until her husband gets home from work. Her only food is fruit that can be left on the bed. The family is ineligible for Medicaid because their annual salary is $12,000. She is ineligible for SSDI because she has always been a housewife and has had no individual income.

- In Miami, a woman has been living with MS for 26 years, has been severely disabled for 5 years and now needs daily care. She has only a few more months before she reaches the cap on her million dollar life-time health insurance policy. Florida has a high-risk health insurance pool with a waiting period of twelve months. Her estimated costs before benefits begin would be $20,000. Difficult as this problem is, it may be worsened because Florida is considering dropping the risk pool next year before she would be eligible.

- In upstate New York, a 45 year old woman with MS has been in a county hospital for the last five years. The woman has a master's degree in education. She uses a wheelchair and is in the hospital because there are no community services. Four and 1/2 years ago her eldest son (then 13) jumped to his death from the highest building in the city.

- We recently had a call from someone in Louisiana. He was concerned for his neighbors. The husband of the neighbor's family has MS and they spent their last dollar on a van so he could get medical care. There are two children, the family has no food and no money and there are no services in the community. The children are now out begging for food.

- In Des Moines, Iowa a doctor with MS is providing care for people with no coverage. She is concerned about what will happen to her patients because her MS is getting worse and she may not be able to practice much longer.

- In West Virginia a 37 year old man with MS who is a CPA is now totally bedridden. He has two children 8 and 10 years of age. He was diagnosed when the family lived in California. They moved to Florida to live with his sister. Both his sister and wife worked, leaving the two young children at home with him. He became cognitively dysfunctional and began to abuse the children. The family then moved to West Virginia to be near his wife's parents.

They currently live in government subsidized housing. The wife cannot accept a cost of living raise because it would put her salary over the limit, driving up the rent.

- A school teacher with MS had to give up her job in New York City because of a lack of services. She still wants to teach, and with some assistance is capable of it.

Members of the Pepper Commission, we have chapters in every state of the country. They tell us they hear these stories every day. Some people are more fortunate and some people are less so. Many will not survive until solutions are put into effect. We urge you to act swiftly to prevent the continuance of problems like these.

The National Multiple Sclerosis Society is available to work with you by providing required data and assistance. We are at your disposal to work toward a solution to the national long-term care crisis.

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